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OXFORD REGIONAL TRAINING COURSE IN CLINICAL
PSYCHOLOGY

Doctorate in Clinical Psychology

Health professionals discussion of dementia with older adults;
an application of the Theory of Planned Behaviour

Suzanne Whitehead

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ABSTRACT

This study investigates the factors which might influence health professionals' decision whether or not to discuss with older adults the implications of their progressive memory problems (dementia). Previous research suggests that few older adults with a diagnosis of dementia are informed of their diagnosis (Rice & Warner, 1994; Wolff, Woods & Reid, 1995). Whilst one study found that the majority of people with dementia said that they wished to know their diagnosis (Wolff *et al.*, 1995).

A questionnaire was developed, based on the Theory of Planned Behaviour, to elicit factors which might predict health professionals' choice of whether to discuss with older adults the implications of their dementia. Reliability was demonstrated for the questionnaire, and it was completed by 184 health professionals (namely, nurses and clinical psychologists). The results indicated that most participants would be likely to discuss dementia with older adults they work with (72-82 percent). The relative importance of the Theory of Planned Behaviour components and the anxiety component were, in descending order: subjective norm, anxiety, and perceived behavioural control. Gender and profession did not significantly influence the results. The more experience participants had of working with older adults with progressive memory problems, the more likely they were to choose to discuss the implications of dementia with their clients. Clinical implications such as facilitating a culture change, methodological issues and avenues for future research are discussed.

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Section 1

INTRODUCTION

1.0 INTRODUCTION

This study investigates whether health professionals choose to discuss the implications of progressive memory problems with the older adults with whom they work. It also investigates the factors that might influence their decision whether or not to do so. The introduction is divided into two parts. The first part covers:

- relevant issues surrounding the area under investigation,
- the diagnosis and definition of dementia, along with definitions of progressive memory problems and what constitutes a caregiver,
- a focus on current clinical practice according to the literature, and
- the context of mental health services provided for older adults.

The second part of the introduction outlines:

- the Theory of Planned Behaviour (Ajzen, 1985, 1988; Ajzen & Madden, 1986) which provides a template to investigate individuals' attitudes, perceived constraints, and real constraints involved in making a decision to carry out a certain behaviour,
- a critical evaluation of the theory,
- a discussion of some of the methodological issues relevant to studies which have applied the Theory of Planned Behaviour in different settings,
- an additional component, anxiety, will be incorporated alongside the theory in response to criticisms of the theory (Ogden, 1996), and
- the research questions and hypotheses.

1.1 DEMENTIA

1.1.1 The diagnosis of dementia

The dementias of later life, and Alzheimer's disease in particular, are not disorders in their own right (Arendt & Jones, 1992). They are complex syndromes of symptoms that show great variability and overlap with other treatable dementias, depression and general ageing processes (Gubruim, 1986; Iliffe, 1995). The difficulty caused for diagnosis by this complexity is discussed in more detail later. However, the dementias have been broadly categorised and some have been shown to have clear aetiologies.

The World Health Organisation provides the following definition of dementia:

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments in cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation. (World Health Organisation, 1992, p. 45).

Approximately 500 000 people in the UK have dementia, and the incidence and prevalence of dementia increase with age (Tobiansky, 1994). At any one time in the UK approximately five percent of people over 65 and 20 percent of people over 80 will have dementia. Dementia can be associated with mental health problems including, for example, depression. The prevalence of depression is estimated at 10 to 13 percent for adults over 65 years (Copeland, Dewey, Wood, Searle, Davidson & McWilliam, 1987; Gurland, Copeland, Kuriansky, Kelleher, Sharpe & Dean, 1983; Morgan, Dallosso, Arie, Byrne, Jones & Waite, 1987). Average age expectancy in the European Community has

increased from 67.6 years for men and 73.4 for women in 1960, to 73.9 years for men and 76.4 years for women in 1990 (Eurostat, 1993a). This suggests that by 2020 there will be twice as many people over 60 years of age living in the European Community as in 1960 (Eurostat, 1993b). Similarly the population of people with dementia is likely to increase substantially.

The most prevalent type of dementia is Alzheimer's disease which accounts for approximately 50 percent of all cases (Tobiansky, 1994). Alzheimer's disease is characterised as having an insidious onset and a gradual progression. The aetiology of Alzheimer's disease is unclear and it may represent an artificial grouping of different disorders which have yet to be differentially identified (Arendt & Jones, 1992). Multi-infarct dementia accounts for 10 to 15 percent of cases and results from cell death caused by small strokes. It occurs among older people with cardiovascular disease, such as hypertension, and has a clear aetiology and a step-wise deterioration as brain cells are damaged by discrete infarcts. In a further 10 to 15 percent of cases both Alzheimer's disease and multi-infarct dementia may be present. There are also several much rarer forms of dementia, including diffuse Lewy body dementia, Parkinson's-related dementia, and Pick's disease.

Strictly speaking, a diagnosis of dementia cannot be made until a post-mortem has been carried out. In practice, older adults who exhibit progressive memory problems are usually given a label of dementia by health professionals. Psychometric tests and brain scans can be used to provide evidence of progressive memory problems, making a probable diagnosis possible. This can enable appropriate interventions to be provided.

There are various hypotheses about the aetiology of dementias, including genetic, viral, biochemical or trauma-induced hypotheses. However as yet, there is no conclusive

evidence for any of these hypotheses (Zarit & Zarit, 1982). It is likely that with increased knowledge and awareness of dementia, and more sophisticated assessment techniques such as magnetic resonance imaging, dementia will be diagnosed earlier (Woods, 1995).

1.1.2 Definitions

To aid clarity, the term **dementia** is used in this research to include all forms of dementia, including Alzheimer's disease. It is acknowledged, however, that this could mask some important differences in experience. The term **progressive memory problems** is taken to be synonymous with dementia, although these are not strictly equivalent terms. The term **progressive memory problems** is often used to compensate for the difficulties of accurate diagnosis of dementia. The deterioration in abilities experienced by people with dementia is such that a member of their social network, usually a member of their family, becomes responsible for many aspects of their care. Again, to aid clarity, **caregiver** or **carer** will be used as a general term to describe such a person, although for people with mild dementia, carer may not be a wholly accurate description of their relationship with this person.

1.1.3 Discussion of a diagnosis of dementia with older adults

There has been a limited amount of research investigating the practice of health professionals in sharing information when they diagnose dementia. Rice & Warner (1994) asked around 250 doctors working with older adults to indicate the frequency with which they gave information on both diagnosis and prognosis to people with dementia and their carers. The survey asked them to make a distinction between people with mild, moderate and severe dementia. The participants were asked to estimate the percentage in each group that they would inform fully. Over 80 percent of the doctors surveyed said that they rarely told a person with severe dementia about their diagnosis and prognosis. In cases of mild or moderate dementia the practice was mixed. In addition, there were

doctors who consistently shared and doctors who consistently withheld information. However, whilst it was variable whether a person with dementia would be told, almost 100 percent of the doctors surveyed said that they told carers. This suggests that there are frequently times when a carer may know of a diagnosis and prognosis whilst the person with dementia does not. This raises difficult ethical questions concerning a patient's "right to know" his/her medical status.

Rice & Warner (1994) also recorded qualitative comments given by participants about the reasons for sharing or not sharing information. Reasons given for not informing fully included:

- the potential stress and harm to the person,
- a need to take cues from the person about how much information to give, and
- a need to be 'economical with the truth' by using terms such as 'brain shrinkage' or 'memory loss' instead of dementia.

Also included in the last category were instances when a diagnosis was given but without a prognosis. Rice & Warner (1994) conclude that 'telling a diagnosis without a prognosis in mild dementia could be seen as similar to using euphemisms' (p. 476).

There are a number of methodological problems which make the results tentative. Terms used in the study were not well defined. For example, the authors acknowledge that 'mild', 'moderate' and 'severe' dementia and 'telling' were not precisely defined and could lead to potentially unreliable results. Secondly, participants were asked to judge their practice retrospectively, without reference to case reports, which could lead to inaccuracy and bias. The possibility of a response bias in favour of reporting what might be seen as socially acceptable practice, rather than actual practice, is not acknowledged.

A prospective study collecting information by taping actual consultations might produce more reliable and valid information.

In a similar study Wolff and colleagues (Wolff, Woods & Reid, 1995) asked a sample of 35 Scottish old age psychiatrists and a representative sample of 35 Glasgow general practitioners whether a person with early dementia should know their diagnosis. One third of the general practitioners and one fifth of psychiatrists were unsure whether the person should know. They reported that only a small majority of consultants would inform the person. They conclude that:

Not surprisingly, there remains doubt about telling the mildly demented patient the diagnosis among both psychiatrists and general practitioners. If there is an expectation of relentless deterioration to a state of incoherence and incontinence, and a 'second infancy', the doctor may prefer to delay the bad news for as long as possible. (p. 67).

These results complement those of Rice & Warner (1994) but are also subject to the same methodological problems, including retrospective reporting. As in Rice & Warner's study (1994), caregivers were invariably told of the diagnosis, while patients with severe dementia were almost never told.

The Alzheimer's Disease and Related Disorder Society (ADARS) investigated the process of health professionals' providing information to older adults with dementia and their carers (Brodsky, Griffin & Hadzi-Pavlovic, 1990). All carers were aware of the diagnosis of dementia, 84 percent had been told by a health professional: specifically just over half by a general practitioner. Most initial diagnoses were considered 'vague' by carers, and two thirds remembered having a discussion about the prognosis. Less than

half of the patients had been told about their diagnosis (39 percent). Of those patients informed, 26 percent had been informed by a relative or friend, and only 13 percent told by a health professional. Regarding prognosis, 75 percent of patients were given no information, and most carers (69 percent) reported that they had trouble talking with the patient about their illness. In most cases the diagnosis was initially given to the carer alone (65 percent) and only 21 percent of carers and patients were informed together. Carers were asked how they would have preferred to have been informed about the diagnosis of dementia. Most of the carers appeared to prefer to be informed initially alone (56 percent). About a third of carers (31 percent) preferred to be told with the patient initially, and only two percent thought the patient should be told alone.

Brodaty and colleagues (Brodaty *et al.*, 1990) found that general practitioners were consulted most frequently about dementia and they were perceived to be helpful. Nurses and social workers were considered most helpful after general practitioners, and clinical psychologists were not considered to be helpful. They conclude that:

In our experience even moderately advanced Alzheimer's disease patients retain some insight and appreciation that their world has changed in a significant manner (Brodaty *et al.*, 1990, p. 369).

The authors appear to be in favour of a diagnosis and prognosis of dementia being shared with the patients themselves. However, Brodaty and colleagues note that 'the correct path for health professionals in discussing the disorder is far from clear' (p. 369).

1.1.4 The views of people without dementia about sharing information

Erde and colleagues (Erde, Nadal, & Scholl, 1988) were interested in the question of whether or not a person in the early stages of dementia, who still had enough insight to

understand the diagnosis, should be told. They investigated this by inferring the views of people with dementia from the views of people without dementia. They conducted their study by showing a sample of 224 American adults without dementia a case vignette of a person with Alzheimer's disease. They then asked them whether or not they would like to be told the diagnosis if they were the person in the vignette. Of the sample, 92 percent said that they would like to be told. The reasons they gave were to plan for the future (94 percent); to get a second opinion (62 percent); to settle affairs (36 percent) and to travel (15 percent).

These figures suggest that a large majority of people would like to be told (Finkelstein *et al.*, 1988). However, there are a number of methodological problems which mean the results of this study should be treated with caution when applying them to people who actually have Alzheimer's disease or dementia. The people asked were not actually in the position of having dementia (Brody & Tomlinson, 1988), and the vignette described worse-case scenario (for example, 'he will be like a new-born baby ... wearing an adult diaper, unable to feed himself' p. 402). Both these factors may have influenced the responses given by the participants. In addition, Brodaty and colleagues (Brodaty *et al.*, 1990) suggest that the generalisability of the results to a UK population may not be possible because of unknown cultural differences in attitudes towards dementia

A small-scale survey investigated carers' views about giving a diagnosis of dementia to their relative who attended a memory clinic (Phillips, 1996). In response to the question 'should the patient always be told the diagnosis?', most carers responded 'don't know' or 'definitely no'. When asked whether or not their relative would want to be told the diagnosis if they could give their opinion, 35 percent of carers said their relative would not want to be told, 14 percent said their relative would want to be told, and 51

percent said they did not know. It seems possible that the views of people without dementia may differ from the views of those with dementia.

1.1.5 The views of people with dementia about sharing information

Wolff and colleagues (Wolff *et al.*, 1995) report an unpublished study of self-referrals to a Glasgow memory clinic where the majority of people said that they wished to know their diagnosis. The study has advantages over Erde and colleagues (Erde *et al.*, 1988) in that it is a finding from a sample of people with memory impairment. However, people who self-refer to a memory clinic might represent a group of people with very different views on sharing diagnosis and the finding may not be generalisable to a wider population of people with dementia. To summarise, this study provides provisional evidence that people with dementia may hold different views about being told their diagnosis to those without dementia, because Erde *et al.*'s study suggests they would like to be informed (1988).

1.1.6 Recent developments in oncology

Oncology research suggests a change in the attitude of health professionals towards discussing a diagnosis of cancer and its implications with patients. In 1961, Novack and colleagues (Novack, Plumer, Smith, Ochitill, Morrow, & Bennett, 1979) found that 90 percent of physicians indicated a preference for not telling a cancer patient his/her diagnosis. By 1979 this had changed to 97 percent of staff indicating a preference to tell a cancer patient his/her diagnosis. Oncology research also highlights the benefits of discussing diagnosis with clients and of how this affects planning of care, emotional adjustment, and discussion of the future by the patient with relatives (Canadian Task Force, 1991; Novack *et al.*, 1979).

1.1.7 Patients' rights

Nowadays, it is generally accepted that patients have a 'right to know' about their illnesses so that they are in a position to make decisions about their future care and treatment (Phillips, 1996). It could be argued that the same applies to individuals suffering from a dementing illness such as Alzheimer's disease. To be able to plan ahead, older adults with dementia need to be informed of the diagnosis as early as possible while the ability to be able to deal with the implications is still a possibility.

1.1.8 Mental Health Service provision for older adults with dementia

The majority of older adults with dementia reside in the community (Bergmann, Foster Justice & Matthews, 1978; Kay, Beamish & Roth, 1964). Appropriate services are tapped, involving family members to provide care and receive respite-care, including day centres and in-patient respite-care

Family members are the main carers (Bergmann *et al.*, 1978) and most of the caregiving takes place in the community with approximately 90 percent of patients with dementia living in the community rather than in institutions (Bergmann *et al.*, 1978; Kay *et al.*, 1964; Zarit, Reever & Bach-Peterson, 1980). However, if families of older adults with progressive memory problems are not informed about the implications of their problems they may not come into contact with services which can help them. Mostly, the focus of service provision concerns the welfare of the caregiver and alleviation of the stress and burden caregiving can involve (Gilleard, 1987). Extreme variations exist within the caregiver role and carers adapt quite differently to similar situations (Zarit *et al.*, 1980). Caregivers require recognition of their work by professionals, such as, planned respite-care, information about dementia, services and benefits, physical help, and continuity of support (Anderson, 1987).

As well as the families requiring information in order to receive appropriate services, the older adults themselves may need to be informed about the implications of their progressive memory problems in order to access services. There is a lack of reference in the literature to the perspective of the older adult with dementia and little concern is shown about the care-recipients¹ experiences (Barer & Johnson, 1990). Although, most studies have concentrated on the well-being of caregivers and their evaluation of the services provided, some studies concerned with the dementia sufferer have been carried out. One study explored the strain older adults with dementia experience of not knowing what is happening to them, keeping it from others, and the fear of being seen as out of control (Keady, Nolan & Gilliard, 1995). Experiences of individuals who want to understand and adjust to aspects of the dementing process include isolation, self-deprecating attitudes and fear, often due to lack of information (Yale, 1991). Cohen (1991) refers to six stages of awareness of a dementing process from recognition and concern that 'something is wrong', to denial, anger, coping, maturation and finally separation from the self. These are reminiscent of some of the stage models of death and dying (e.g. Kubler-Ross, 1985). Other studies have suggested that support groups successfully help people in the early stages of dementia (Gillies, 1995). Participants of these support groups cite some positive effects, including improved self-esteem and coping abilities, increased understanding of their condition, and decreased isolation.

It has been proposed that skilled care for older adults with dementia should incorporate person-centred care (Jones & Miesen, 1992; Kitwood & Benson, 1995). This entails respecting individuality, maintaining agency, validating feelings, and exercising abilities. A summary of this approach includes a celebration of life, providing pleasure

¹The older adult with dementia who is cared for by a relative or friend.

to the senses and support (Kitwood, 1995). Older adults need empowerment, not just in health services, but among all agencies including local authority community care-planning, retirement and housing policies.

Kitwood proposes that dementia is not simply a neurological disease, and challenges the traditional medical model of dementia (Kitwood & Bredin, 1997). As such, he states that dementia affects the sufferer's 'personhood'. The personhood of an individual emerges in a social context. As such, personhood is provided through relationships and their inter-subjectivity. Personhood also consists of the dementia sufferers' view of themselves. Thus, Kitwood postulates that being diagnosed with dementia affects the sufferer's view of themselves. As such, if information about the diagnosis and implications of older adults progressive memory problems is withheld, it will affect the sufferer's as individuals. It is frequently thought that older adults with dementia have depleted communication skills. However, Goldsmith (1996, p. 10) states that people with dementia retain a capacity to communicate and to describe their experience of dementia. Thus, it may be possible to ask older adults with dementia whether they want to be told about the implications of their disease or not.

1.2 MODELS OF DECISION-MAKING

1.2.1 Health professionals' decision-making

Several models of decision-making were investigated that might help to answer the main research questions. I shall outline briefly two of these models, followed by the one chosen, the Theory of Planned Behaviour (section 1.2.2), for the current study.

The search for possible models to help answer the research questions uncovered three decision-making theories. I shall outline here briefly the Transtheoretical Model of Behaviour Change (Prochaska & DiClemente, 1982), the Health Action Process

Approach (Schwarzer, 1992) and (in section 1.2.3) the Theory of Planned Behaviour (Ajzen, 1985, 1988, 1991; Ajzen & Madden, 1986). These all incorporate health beliefs and can be considered to be cognitive models of explaining behaviour.

The Transtheoretical Model of Behaviour Change suggests stages of behaviour change. These are:

1. Precontemplation - not intending to make any changes.
2. Contemplation - considering a change.
3. Preparation - making small changes.
4. Action - actively engaging in a new behaviour.
5. Maintenance - sustaining the change over time.

This model has been applied to several health-related behaviours, including smoking, alcohol use, exercise and screening behaviour (DiClemente, Prochaska, Fairhurst, Velicer, Velasquez & Rossi, 1991; Marcus, Rakowski & Rossi, 1992). For each different stage the model suggests a set of beliefs and behaviours. Individuals may progress through the stages, move back, and then onwards.

Similarly, the Health Action Process Approach highlights the need to include a temporal element in the understanding of beliefs and behaviour. In addition, it emphasises the importance of self-efficacy as a determinant of both behavioural intentions and self-reports of behaviour. This theory differs from others, but is similar to the transtheoretical model, mainly because it includes a distinction between a decision-making/motivational stage and an action/maintenance stage. Thus, the model adds a temporal and process factor to understanding the relationship between beliefs and behaviour and suggests that individuals initially decide whether or not to carry out a

behaviour (motivation stage) and then make plans to initiate and maintain this behaviour (action phase).

The individual components of the Health Action Process Approach have been tested and studies have provided some support for the model. In particular, Schwarzer (1992) claimed that self-efficacy is consistently the best predictor of behavioural intentions and behaviour change for a variety of behaviours, including the intention to make effective use of contraception, breast self-examination, drug users' intentions to use clean needles, intentions to stop smoking, and intentions to adhere to weight loss programmes and exercise programmes (e.g. Beck & Lund, 1981; Seydal, Taal & Wiegman, 1990).

1.2.2 The Theory of Planned Behaviour

Several models have been developed in order to understand social behaviours. The Theory of Planned Behaviour is one of these models and is derived from the Theory of Reasoned Action (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). The Theory of Reasoned Action has been used extensively to examine factors predicting behaviours (Ogden, 1996). It is seen as an important model because it places the individual within their social context. It emphasises the importance of subjective norms, that is, an individual's beliefs about their social world, and how this can affect the carrying out of certain behaviours. This is in contrast to the more traditional approaches to behaviour prediction. It also emphasises the importance of attitude.

Overall, the Theory of Reasoned Action has proved helpful in understanding the decision-making processes which underlie behaviours, especially when describing behaviours that are totally under volitional control (Godin, Valois, Lepage & Desharnais, 1992). However, most behaviours are located at some point along a continuum that

extends from total control to a complete lack of control. An individual has total control when there are no constraints of any type in carrying out a given behaviour. At the opposite extreme, there is a complete lack of control if carrying out the behaviour requires opportunities, resources, or skills which are currently lacking. To take into account such barriers, real and perceived, Ajzen (1985, 1988, 1991) added the concept of perceived behavioural control to the Theory of Reasoned Action. The resulting theory is known as the Theory of Planned Behaviour.

1.2.3 Description of the Theory of Planned Behaviour

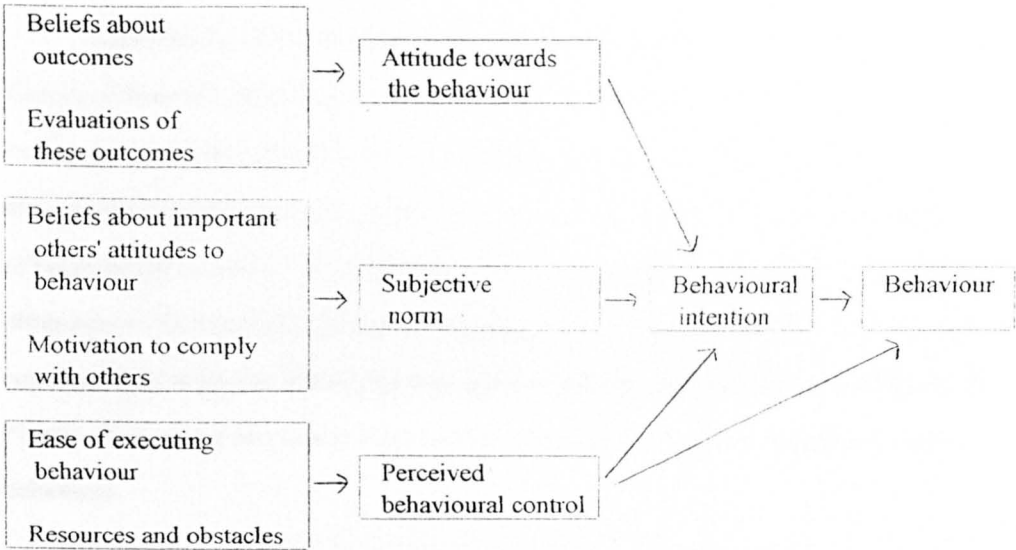
The Theory of Planned Behaviour proposes that intentions should be conceptualised as 'plans of action in pursuit of behavioural goals' (Ajzen & Madden, 1986, p. 456) and are a result of the following beliefs:

1. **Attitude towards a behaviour**, which is composed of beliefs about the outcome of the behaviour (e.g. 'exercising is fun and will improve my health') and evaluation, both positive or negative, of a particular behaviour.
2. **Subjective norm**, which is composed of the perception of social norms and pressures to perform a behaviour together with an evaluation of whether the individual is motivated to comply with this pressure (e.g. 'people who are important to me will approve if I lose weight and I want their approval').
3. **Perceived behavioural control**, which is composed of a belief about the ease with which an individual can execute a behaviour, and beliefs about resources and obstacles related to the particular behaviour. These resources and obstacles are based on either internal control factors (e.g. skills, abilities, information) or external control factors (e.g.

obstacles, opportunities), both of which relate to past behaviour (e.g. 'I found exercising in the past physically strenuous').

According to the Theory of Planned Behaviour (see Figure 1), these three factors predict behavioural intentions, which are then assumed to translate into behaviour. The theory also states that perceived behavioural control can have a direct affect on behaviour without the mediating effect of behavioural intentions.

Figure 1: Model of the Theory of Planned Behaviour



Several studies have tested the relative effect of attitude, subjective norm and perceived behavioural control on behavioural intentions to carry out various behaviours. One of the three main components of the theory, namely attitude, was found to be the sole predictive component in one study (Conner, Martin, Silverdale & Grogan, 1996). Conner and colleagues (1996) found that individuals' intentions to diet were significantly predicted by their beliefs about the possible positive outcomes of dieting. In contrast,

Terry & O'Leary (1995) found that perceived behavioural control was the most predictive component in their study investigating exercise. Other studies have found that all three main components of the Theory of Planned Behaviour each play a part in predicting behaviour and/or behavioural intention (Parker, Manstead & Stradling, 1995; Traeen & Nordlund, 1993). For example, Traeen & Nordlund (1993) found that the relative importance of the model's components were, in descending order: perceived behavioural control, attitude and subjective norm. In this study, all three components explained a proportion of the variance concerning the behaviour of regularly visiting public places to drink alcohol.

Some studies have included other components alongside those specified in the Theory of Planned Behaviour in order to explain a proportion of the variance. For example, Raats and colleagues (Raats, Shepherd & Sparks, 1995) included moral dimensions alongside the three main constructs of the theory which enhanced prediction of behavioural intention. As such, this study found that a measure of perceived moral obligation to family health predicted intentions concerning consuming milk of a lower fat content. This study illustrates that the addition of other components to the Theory of Planned Behaviour can enhance prediction of specific behavioural intentions and/or behaviour.

To summarise, the Theory of Planned Behaviour provides a comprehensive theory of behaviour and decision-making. It appears that, depending upon the behaviour under investigation, the components of the Theory of Planned Behaviour differentially predict individuals' intention to perform behaviour. Overall, the predictions made by the theory have received empirical support (Ajzen, 1987; Ajzen & Madden, 1986).

The Theory of Planned Behaviour has not previously been used as a framework or template for health professionals behaviour. Nevertheless, as noted above, the theoretical framework has been used by clinical psychologists in clinical settings to investigate and predict various behaviours including physical exercise (Norman & Smith, 1995; Traeen & Nordlund, 1993), blood donation (Giles & Cairns, 1995), visiting public houses (Traeen & Nordlund, 1993) and smoking behaviour (Godin *et al.*, 1992). These studies have found that using the framework of the theory is helpful in enabling actions to be predicted.

1.2.4 Methodological problems with studies using the Theory of Planned Behaviour

Several methodological problems have been highlighted concerning research applying the Theory of Planned Behaviour. These include a lack of operational definitions (Godin *et al.*, 1992), for example, of variables such as intention. One study did not include the necessary action, context and time elements (Mullen, Hersey & Iverson, 1987) which have been thought important by others (Ajzen 1985, 1988; Ajzen & Madden, 1986). It is also possible, on occasion, that two variables may be measuring the same thing, for example, in the Dzewaltowski, Noble & Shaw (1990) study the correlation between "self-efficacy" and "intention" was .81. Thus the self-efficacy and intention components could be the same construct but with different names. Indeed, a given variable might not measure what the authors might think. For example, Sallis, Hovell, Hofstetter, Faucher, Elder, Blanchard, Casperson, Powell & Christenson (1989), found that perceived "barriers to exercise" corresponded to intention and attitudinal dimensions rather than to questions assessing aspects of perceived control.

Accurate documentation of the psychometric qualities of variables and actual behaviour are also needed. For example, Valois & Godin (1991) have shown that internal consistency of the attitudinal scale is related to the quality of prediction of

behaviour: the lower the internal consistency of the scale, the lower the relation to the behaviour. More rigorous application of methodological design are needed, for example, when researchers using the social-cognition theories develop questionnaires.

1.2.5 Response rates

Godin and colleagues (Godin *et al.*, 1992) noted that the rate of response in their study concerning predictors of smoking behaviour, using the Theory of Planned Behaviour, was in the range of the average questionnaire survey in the general population (32 percent). Many authors have expressed caution against expecting mail survey questionnaire response from a general population to exceed 30 percent (Black & Champion, 1976; Goyder, 1985; Labovitz & Hagedorn, 1971; Meyers & Grossen, 1974). Nevertheless, low response rates leave studies open to possible bias. In one study (Godin *et al.*, 1992), bias might be introduced by the decreased participation of smokers. People who smoke might have declined participation in a study that was primarily interested in non-smoking behaviour.

1.2.6 Reliability of studies using the Theory of Planned Behaviour

Several studies have assessed the internal consistency of questionnaires designed to assess the different components of the Theory of Planned Behaviour. These include Ajzen & Madden (1986) who found that their first and second questionnaires had an alpha coefficient of .78 and .87 respectively. While Terry & O'Leary (1995) found that the alpha coefficient for the questionnaire used in their study was .77. These results indicate high levels of internal consistency. However, some studies have not included this internal consistency assessment (Conner *et al.*, 1996; Traen & Nordlund, 1993). Previous studies utilising the Theory of Planned Behaviour have also not assessed test-retest reliability, which weakens the conclusions that can be drawn from their results (e.g.

Beale & Manstead, 1991; Conner *et al.*, 1996; Reinecke, Schmidt & Ajzen, 1996; Terry & O'Leary, 1995; Traeen & Nordlund, 1993).

1.2.7 Validity of studies using the Theory of Planned Behaviour

The Theory of Planned Behaviour has been used to assess a variety of health-related behaviours. For example, Brubaker and Wickersham (1990) examined the role of the theory's different components in predicting testicular self-examination and reported that attitude towards the behaviour, subjective norm and behavioural control correlated with the intention to perform the behaviour. Other studies evaluating the theory have indicated that the components of the model do indeed predict the behaviour being studied (e.g. Beale & Manstead, 1991; Giles & Cairns, 1995; Schifter & Ajzen, 1985; Terry & O'Leary, 1995; Traeen & Nordlund, 1993).

The proportion of the variance accounted for by the Theory of Planned Behaviour has varied in reported studies. Significant explanations of the variance range from 20 to 68 percent for the three main components of the theory (Ajzen & Madden, 1986; Traeen & Nordlund, 1993; Parker *et al.*, 1995). Some studies have incorporated additional components alongside the theory to explain a proportion of the variance. For example, Raats and colleagues (Raats *et al.*, 1995) found that the components of the theory explained 29 percent of participants' intentions to reduce fat (full-fat milk) in their diet. The addition of a perceived moral obligation measure explained a small but significant proportion of the variance, with the final explanation accounting for 31 percent of the variance.

1.2.8 Anxiety component

Ogden (1996) suggests that a factor missing from the Theory of Planned Behaviour is a measure of affect. Anxiety can influence behaviour, for example, when an appraisal or

perception of threat inhibits behaviour (Hawton, Salkovskis, Kirk & Clark, 1989). Increased anxiety may be mediated by many factors. In the area of dementia, this could for example be the relationship of the health professional to the client, the length of experience working in the area, or fear of discussing dementia by the professional. Existing studies have not included a measure of affect within their questionnaire designs'.

1.3 SUMMARY AND RATIONALE for the current study

Within the older adult literature, it seems apparent that some health professionals (namely, general practitioners and Consultant Psychiatrists) fail to inform some patients with dementia about their diagnosis and the implications of their disease (Rice & Warner, 1994). However, it seems that a majority of older adults would want to be told if they were diagnosed with dementia (Erde *et al.*, 1988; Wolff *et al.*, 1995). There has been a change in the attitude of health professionals to discussing a diagnosis of cancer and its implications with patients. However, this does not seem to have happened with health professionals working with older adults with dementia.

There is little research to suggest whether or not older adults with progressive memory problems would make changes if health professionals discussed with them the implications of their difficulties. In the current study, it will not be assumed that discussing the implications of their dementia with older adults would cause them to make positive changes, as there is currently little literature to support this assumption. However, the benefits of early identification of dementia, diagnosis and discussion of prognosis could allow for older adults and their families to mobilise a response. Older adults may then be able to access appropriate services, or consider moving to a more protective environment. Caregivers may become involved in a support group where they can gain advice, support and information (Canadian Task Force, 1991).

The reasons why health professionals prefer not to tell older adults about their diagnosis of dementia and discuss its implications appears to be complex. For example, health professionals may have the attitude that older adults will forget such discussions. They may fear that older adults will become distressed and, perhaps, even take their own lives as a result of the information. In addition, health professionals may work within an organisation where discussing the implications of progressive memory problems with older adults themselves remains a taboo subject and is not part of everyday practice. Finally, even if health professionals do decide to discuss such matters with the older adults they work with, they may perceive this task not to be within their full control. Several factors may impede such a discussion, including a physical environment not conducive to such discussions, having inappropriate skills, or lacking appropriate information to give to older adults to aid them in an understanding of their progressive memory problems. Thus, there may be many factors which inhibit health professionals from carrying out such a task: factors which are both real and perceived. They may also include anxiety on the part of the health professional.

The current study has taken note of the methodological problems in previous studies which have used the Theory of Planned Behaviour. To summarise these include a lack of operational definitions; not stipulating the action, context and time elements; and a lack of a test-retest design to assess the reliability of the measure employed. Accurate documentation of the psychometric qualities of variables and actual behaviour are also required. The study also takes note of the growing body of evidence (e.g. Norman & Smith, 1995; Schifter & Ajzen, 1985; Traeen & Nordlund, 1993) which indicates that if a time and context are specified closely, then actual behaviour can assume to be predicted by components of the model. Indeed, if specific behavioural intentions are assessed rather than vague ones (e.g. regularly visiting public places to drink alcohol), then actual behaviour is even more likely to be predicted by components of the theory.

To summarise, this Introduction has provided examples indicating that intentions to carry out particular behaviours as well as actual behaviours are significantly predicted by either a combination of, or single beliefs, concerning attitude, subjective norm, and perceived behavioural control (Conner *et al.*, 1996; Parker *et al.*, 1995; Raats *et al.*, 1995; Terry & O'Leary, 1995; Traeen & Nordlund, 1993). Thus, the Theory of Planned Behaviour appears to be a useful framework for predicting both behavioural intention and actual behaviour, and will be used in the current study.

1.4 RESEARCH QUESTIONS AND HYPOTHESES

The current study aims to investigate the factors influencing health professionals when deciding whether or not to discuss with older adults the implications of their progressive memory problems (dementia). This study aims to survey the views of health professionals (specifically, qualified nurses and clinical psychologist's working with older adults with dementia) concerning this issue. The study will investigate whether these health professionals do regularly, that is at least once a month², discuss with older adults the implications of their progressive memory problems. It will also investigate the factors influencing this decision-making process.

The study is based on the Theory of Planned Behaviour (Ajzen, 1985, 1983; Ajzen & Madden, 1986) which is a model of human decision making behaviour and which originates from social psychology. It will seek to determine whether the Theory of Planned Behaviour is useful when investigating factors that influence the decision-making of health professionals in this area. As noted above, additional constructs may be

²The decision to propose that a regular discussion about dementia with clients was at least one a month was based on experience of working in clinical settings and consultation with research supervisors. This frequency chosen should be treated with caution as the experience of those questioned about frequency may be atypical to a majority of other professionals.

added to the Theory of Planned Behaviour to improve prediction of the behaviour being investigated (Parker *et al.*, 1995). Thus an anxiety component has been added to this study. All three main constructs of the theory are assumed to influence prediction of health professionals decisions to discuss the implications of progressive memory problems with older adults. This assumption is based on previous findings in other areas.

The current study also intends to pilot a draft questionnaire (derived from the template provided by the Theory of Planned Behaviour) in order to assess reliability both of a draft and of a revised questionnaire. Cronbach's alpha coefficient tests will be used to check the internal consistency of the questionnaire used in the pilot and main stage of this study. Repeat mailing of the revised questionnaire will be used with a subgroup of participants to assess the test-retest reliability. A vignette will be employed in order to assess participants' behavioural intentions.

1.4.1 Research questions

This study aims to ask the following research questions:

1. Do health professionals discuss with older adults the implications of their progressive memory problems (dementia) ?
2. What factors influence a health professionals' decision to discuss this with older adults ?
3. Is the Theory of Planned Behaviour useful when investigating this decision process ?

1.4.2 Hypotheses

Hypothesis 1

Health professionals regularly discuss (i.e. at least once a month) with older adults the implications of their progressive memory problems (dementia).

Hypothesis 2

There will be an association between behavioural intention and attitude, that is, the degree to which health professionals view discussing with older adults the implications of progressive memory problems in a positive way will predict their behaviour.

Hypothesis 3

There will be an association between behavioural intention and subjective norm, that is, the degree to which health professionals are influenced by other people's views about discussing this with older adults in a positive way will predict their behaviour.

Hypothesis 4

There will be an association between behavioural intention and perceived behavioural control, that is, the degree to which health professionals consider they have control over discussing this with older adults will predict their behaviour.

Hypothesis 5

The degree to which the 'behaviour' is considered anxiety provoking will be negatively associated with intention to perform the behaviour (that is, perceived behavioural intention). For example, if a health professional is anxious about discussing with older adults the implications of their progressive memory problems, the professional is less likely to have a intention to discuss such matters.

The information obtained in this study also provides the possibility of investigating whether any factors, other than the Theory of Planned Behaviour, play an important role in explaining the data. It may be that nurses and clinical psychologists have a different training and thus hold different views about the decision whether or not to talk with older adults about the implications of their dementia. There may also be differences due to gender and the length of experience.

Section 2

METHOD

2.0 METHOD

This section outlines:

- the experimental design of the study,
- the participants,
- the development of the questionnaire,
- piloting of the questionnaire,
- the procedure of the main study,
- the test-retest procedures,
- the submission for ethical approval,
- the steps taken to ensure anonymity, and
- dissemination of the results.

2.3 MEASURE - Development of the questionnaire

Demographic details of the participant group are presented at the beginning of the Results section.

2.1 EXPERIMENTAL DESIGN

A draft version of a questionnaire based on the Theory of Planned Behaviour template (see section 2.3.2) was developed based on interviews with a representative sample of the group. For the main study a survey design, using the revised questionnaire developed from the piloted draft questionnaire, which operationalised the Theory of Planned Behaviour, was employed. A vignette describing an older adult with progressive memory problems (dementia) was incorporated into the questionnaire, along with a self-assessment of participants' behaviour in the past month, and a further factor of anxiety.

2.2 PARTICIPANTS

The participants in the current study were qualified nurses and Clinical Psychologists who had worked within mental health services for older adults with dementia for longer than six months. Participants were excluded if they were unqualified and if they had not worked with older adults with dementia for six months. Participants were recruited through a Psychologists' Special Interest Group in the Elderly (P.S.I.G.E.), a country-wide organisation, and from nurses in three mental health services for older adults. The total number of questionnaires distributed could not be specified accurately because the investigator was not able to have full control of the distribution process (see section 2.5.2). However, an estimated number distributed for the main study is approximately 450 questionnaires.

2.3 MEASURE - Development of the questionnaire

2.3.1 Initial interviews

A draft version of the questionnaire was developed from interviews with 13 representative people. These initial interviews aimed to establish potential domains for beliefs, using the template of the Theory of Planned Behaviour. Participants were interviewed about potential beliefs to cover the areas of **attitude**, **subjective norm** and **perceived behavioural control**. Those interviewed included male and female qualified nurses and clinical psychologists. They were chosen to represent those who were trained recently and those who were more experienced; those who were working with organically ill patients, and those working with functionally ill patients.

Each interview was semi-structured and lasted between 20 to 35 minutes. The interviews took place in a quiet room adjoining the participants' workplace. The structure of these interviews was based on that suggested by the Theory of Planned Behaviour (Ajzen & Fishbein, 1980). In addition, the investigator provided a verbal

preamble to each interviewee emphasizing that the information would be used to help design a questionnaire and would be confidential. Each interviewee was told that the investigator did not have wide experience within this speciality, but was curious about and interested in researching this area. This aimed to provide a non-threatening environment for the interviewee to share their views based on their experience. It was also made clear that the investigator was interested in any views about the topic, positive or negative. A brief description was also given about the nature of the study, similar to the information provided on the information sheet sent out with the questionnaire (see section 2.3.3).

Questions asked as part of the semi-structured interview were as follows:

1. What are the advantages, as you see them, of talking to older adults about the implications of their progressive memory problems?
2. What are the disadvantages, as you see them, of talking to older adults about the implications of their progressive memory problems?
3. Are there groups of people or individuals who would approve if you chose to talk to older adults about the implications of their progressive memory problems?
4. Are there groups of people or individuals who would disapprove if you chose to talk to older adults about the implications of their progressive memory problems?
5. Can you think of anything which would make talking to older adults about the implications of their progressive memory problems easy as you see it ?
6. Can you think of anything which would make talking to older adults about the implications of their progressive memory problems difficult as you see it ?

Demographic data was also collected at the end of each interview to assess the heterogeneous composition of the group. During each interview, the investigator

Section 3

RESULTS

facilitated discussion surrounding each question and recorded this information by hand. Interviewees were thanked for their co-operation with this early stage in the development of a questionnaire.

These interviews provided items for the attitude, subjective norm and perceived behavioural control parts of the Theory of Planned Behaviour. Items suggested by those interviewed as likely to be relevant to making a decision whether or not to discuss the implications of progressive memory problems with older adults (the behaviour) included whether participants believed they would cause the patient intense psychological distress by discussing these matters (**attitude** towards the behaviour), whether or not their colleagues discussed this with patients (**subjective norm**), and the participants' professional training (internal **perceived behavioural control** factor).

The different items suggested, covering attitude, subjective norm and perceived behavioural control suggested by those interviewed, were listed and tallied to provide the most frequently mentioned items (see Tables 1-3). The tallying process was carried out by another trainee clinical psychologist. Inter-rater reliability was calculated for categories in eight interviews ($n=8$) using Cohens Kappa, eliciting an overall value of 0.66. This indicated a 'substantial' agreement between judges (95 percent confidence interval) (Landis & Koch, 1977). Draft versions of the questionnaire were discussed with an experienced research psychologist, a Professor of Social Sciences lecturing on the Theory of Planned Behaviour, and dissertation supervisors.

Table 1: Health professionals' attitudes: the most salient beliefs about the consequences of discussions identified through interviews

Distress the older adult
Make plans for the future ie financial, power of attorney, type of care want in future
Prompts treatment
Older adult starts coping
Older adult gains understanding
Fear of the future develops
Older adult acknowledges the problems they are having
Explain symptoms/provide information about the nature of dementia
Older adult forgets what they were told
Older adult becomes depressed

Table 2: Views about subjective norm: the most salient beliefs about who were 'important others' identified through interviews

Consultant Psychiatrist
General Practitioner
Family/relatives
Main carer
Nurses/Community Psychiatric Nurses
Clinical Psychologists
The older adult themselves

Table 3: The most salient beliefs about perceived behavioural control factors or conditions identified through interviews

Time to talk to older adult patients and follow-up
Good relationship with the older adult
Good relationship with the older adults' carer/relatives
An appropriate environment which is quiet
Support of other professionals
Training and skills to talk to older adults about the implications of their illness
Distressing the older adult
Literature to give the older adults about dementia
Adequate service provision

2.3.2 Design and layout for a draft questionnaire

The investigator consulted up-to-date books to help with the questionnaire design and layout (e.g. Oppenheim, 1992). All components of the theory were incorporated into a draft questionnaire (Ajzen, 1985, 1988, 1991; Ajzen & Madden, 1986).

Three items were included in order to assess participants' behavioural intentions. One item asked participants 'how likely is it that you will discuss the implications of dementia with these older adults?' relating to some time in the next month. This item provided the first global assessment of participants' behavioural intention to discuss such matters. A second global assessment item for behavioural intention was used, 'I will talk to the older adults I work with ...at some time over the next month'. A third assessment of behavioural intention was designed whereby a vignette was generated describing an older adult with a diagnosis of mild dementia. This was devised in conjunction with the investigator's supervisors, a consultant clinical psychologist working in the area and a qualified nurse working on a ward for organically-ill patients. Participants were asked to relate their answers to the vignette for this item which appeared in Part 1 of the

questionnaire. Also, in part 1, appeared a self-assessment of behaviour over the past month. All the item scales used in the questionnaire were semantic-differential scales as suggested by the original theory (Ajzen & Fishbein, 1980), the only exception to this rule was the self-assessment of past behaviour which had five frequency options.

The investigator decided to layout the draft questionnaire as shown in the Theory of Planned Behaviour (see Figure 1 in Introduction) and because no specific guidance is given by the original theory. As such, items concerning **attitude** appeared in Part 2, items concerning **subjective norm** appeared in Part 3, and finally items concerning **perceived behavioural control** appeared in Part 4. Part 5 consisted of demographic information and Part 6 comprised the re-test option. Finally, there was space for participants to write their views about the questionnaire and a statement thanking them for taking the time to complete the questionnaire. It was decided to include the demographic details at the end of the questionnaire as the literature indicates that this is preferable to the start (Oppenheim, 1992). It was felt that participants might be more inclined to complete the whole questionnaire if they were asked questions relevant to the subject matter rather than being asked to reveal personal details before knowing what sort of questions they were going to be asked.

Parts 2-4 consisted of three main sections representing the three constructs derived from the Theory of Planned Behaviour, and one additional factor. As indicated in the Introduction (section 1.2.3) each of the three main constructs can be subdivided into two components. For example, **attitude** can be divided into 'beliefs about outcomes of a specified behaviour' and 'evaluations of these outcomes'. These two components can make up attitude. The first construct, attitude, is regarded as a 'global direct' measure, using the language of the original theory (Ajzen, 1985, 1988; Ajzen & Madden, 1986). The latter two components are regarded as 'indirect measures' by the theory. The same is

true of the other two constructs: both **subjective norm** and **perceived behavioural control** can be subdivided into two components each. The former constructs are known as global direct measures, and the latter components as indirect measures. As such, Part 2 comprised initially of six items covering the global direct measure of attitude. The latter section of Part 2 comprised firstly of ten items related to 'beliefs about outcomes of a specified behaviour', and then ten items related to 'evaluations of these outcomes'. Part 3 comprised initially of two items related to the global direct measure of subjective norm. The latter section of Part 3 comprised firstly of seven items related to 'beliefs about important others' attitudes to behaviour' and then seven items related to 'motivation to comply with others'.

Part 4 comprised initially of four items related to the global direct measure of perceived behavioural control. Firstly, it comprised of nine items related to indirect measures of 'perceived behavioural control factors'. These were possible factors which could make discussing the implications of dementia easier and participants were asked to rate the likelihood of each occurring. Then nine items related to the same 'perceived behavioural control factors' were presented for participants to rate the extent each would increase the likelihood they would discuss such matters. One further factor, a measure of negative affect, which may predict participants' intentions to carry out behaviour, was added to the questionnaire. As such, four items relating to anxiety were designed in conjunction with the investigator's supervisors, and appeared at the end of part 4. These four items were similar to the 'global direct' measures which make up the three main components of the Theory of Planned Behaviour.

2.3.3 Design and layout of a draft information sheet

An information sheet was designed to provide relevant details about the dissertation project. A short preamble was designed aiming to gain participants attention and make

the study relevant to them. Details concerning ethical approval and consent from Managers to approach nursing staff were described. In addition it was highlighted that information provided by participants would be confidential and no details would be fed back to Managers which would identify certain staff. It was also indicated that a summary sheet of the results and implications would be made available to those interested. An address and contact number was provided for participants to contact the investigator or supervisors with any questions.

It was requested that those who completed the questionnaire had worked in the speciality for more than six months, had clinical contact with older adults with dementia over the last six months, and had a professional qualification as a nurse or clinical psychologist. Otherwise it was requested that the questionnaire be returned in the enclosed stamped addressed envelope, or be passed onto someone appropriate to complete. It was noted that the investigator was making plans to feedback the results of the study to those interested. The information sheets were printed on one sheet of headed paper with the relevant Clinical Psychology training course details.

2.3.4 Design and layout of a draft instructions sheet

An instructions sheet was designed in order to guide participants through completion of the questionnaire (appendix 1). The aim of the study was stated, that the investigator was interested in participants' attitudes towards talking to older adults they worked with about the implications of their progressive memory problems. As in the information sheet, it was made clear who the questionnaires were designed for. A short statement was made about the repetitive nature of the questionnaire. This aimed to acknowledge any irritation with the structure of the questionnaire in advance. In addition, it was made clear that participants comments would be welcome at the end of the questionnaire.

General instructions were outlined similar to those suggested by the theory (Ajzen & Fishbein, 1980). A summary of these instructions were placed in a box to highlight how to complete the seven point scales, and were followed by the general instructions. A contact address and telephone number was provided at the bottom of the instructions page. Participants were thanked in advance for their interest in this research. The instructions sheet was printed on one sheet of headed paper similar to the information sheet.

2.3.5 Consultations about development of the draft questionnaire

2.3.5.1 Readability of the draft questionnaire

Eleven qualified nurses and clinical psychologists were consulted about the design of the draft questionnaire and vignette. This aimed to assess readability of the questionnaire. Individuals were asked to comment on the questions and to identify irrelevant or ambiguous items. The information received was discussed with the investigator's supervisors and final amendments made to the questionnaire before the piloting stage.

2.3.5.2 Face validity

The draft questionnaire, information and instructions sheets were shown to a nurse and clinical psychologist to ensure face validity and minimal changes were suggested. Amendments were made only to the instructions sheet and involved moving the general instructions to appear before the summary section. The summary box used bullet points to provide a quick reference point for participants. This appeared clearer to read.

2.3.5.3 Minor amendments to the information sheet

In response to feedback obtained by the investigator when visiting Managers to discuss the study, two further changes were made to the information sheet. The two changes made are outlined in brief as follows:

- The information sheet was amended to address feedback from managers about why medical staff (e.g. Consultant Psychiatrists and general practitioners) had not been included in the study. It was made clear that there had already been studies carried out with these two groups, but that there was less literature concerning nurses and clinical psychologists.
- The information sheet was also amended so that participants knew it would take twenty minutes maximum to complete the questionnaire. This information aimed to increase response rates.

2.3.6 Final amendments to the draft questionnaire and information sheet

The draft questionnaire and information sheet were amended and developed to create a revised questionnaire and information sheet which were easily read (appendices 2-3). Most of the changes for the revised questionnaire from the draft one consisted of moving or deleting specific items, clarifying the wording and the instructions. However, the basic design of the revised questionnaire remained the same as the draft (in section 2.3.2) apart from the final changes detailed in appendix 4.

2.4 PILOTING THE REVISED QUESTIONNAIRE

2.4.1 Distribution of the revised questionnaire

The draft questionnaire and vignette were developed and amended as outlined above (section 2.3.6) and the revised version was sent to approximately 36 participants in order to pilot the questionnaire. The information sheet explaining the rationale for the study was enclosed together with a stamped addressed envelope for return. The instructions sheet was also enclosed with the questionnaire. This pilot stage aimed to pilot the revised questionnaire and vignette for their statistical properties with a group of nurses and clinical psychologists. Piloting checked that the Theory of Planned Behaviour was

relevant to discussing the implications of progressive memory problems with older adults. Internal consistency using Cronbach's alpha coefficient was calculated for the subscales. A minimum return-rate of 25 revised questionnaires was required for this internal consistency check. This is reported in section 2.4.3 below.

2.4.2 Revised questionnaire response rates

A response rate of 31 revised questionnaires were received from the total (n=36), indicating an 86 percent response rate (see Table 4).

Table 4: Revised questionnaire response rates

Distribution to:	Total No.	Return Rates
Nursing Staff	18	13
Clinical Psychologists	18	18

Of the nursing staff who returned completed revised questionnaires (n= 31), nine were female and four were male. Of the clinical psychologist group who returned completed revised questionnaires, 11 were female and seven were male.

2.4.3 Internal reliability of the revised questionnaire

As mentioned in the Introduction (section 1.2.6), several studies have assessed the internal consistency of the questionnaire designs based upon the Theory of Planned Behaviour framework (Ajzen & Madden, 1986; Terry & O'Leary, 1995). Whereas other studies have not assessed the internal consistency of their questionnaires (Conner *et al.*, 1996; Traeen & Nordlund, 1993). Valois & Godin (1991) indicated that internal

consistency of an attitudinal scale is related to the quality of prediction of behaviour: the lower the internal consistency of the scale, the lower the relation to the behaviour. The internal consistency of the revised questionnaires was assessed (see below), and a test-retest design employed (see section 2.5.3).

Cronbach alpha coefficient tests were carried on data from the revised questionnaire responses, in the pilot stage, to assess its' internal reliability. A mean alpha coefficient of .88 was obtained (n=31). This was consistent with other studies using the Theory of Planned Behaviour. The alpha coefficients for each part of questionnaire (i.e. the theory and anxiety components) are presented in Table 5. As such, alpha values were obtained for the direct and indirect measures comprising attitude, subjective norm, and perceived behavioural control. The two items assessing anxiety were also assessed for internal reliability.

Table 5: Cronbach alpha values for each part of the revised questionnaire in the pilot stage

Components	Alpha values	Number of items
Direct attitude	.69	6
Indirect attitude	.65	18
Direct subjective norm	.91	2
Indirect subjective norm	.81	14
Direct perceived behavioural control	.70	4
Indirect perceived behavioural control	.86	18
Anxiety	.73	2

Table 5 indicates that the alpha values ranged between .65 to .91 for the different sections of the questionnaire. The mean alpha value obtained in the pilot stage was consistent with other studies and indicate satisfactory levels of internal reliability. This also indicates that the revised questionnaire was sufficiently reliable to continue onto the main study, and to use the same questionnaire.

2.5 PROCEDURE

2.5.1 Main study

The revised questionnaire and vignette were distributed to participants, along with instructions to complete the questionnaire, a covering letter and a stamped addressed envelope for return. Approximately 450 revised questionnaires were distributed. Approximately 150 questionnaires were distributed to nursing staff, and approximately 300 were distributed to clinical psychologists.

Steps were taken to ensure a good response rate, including visiting nurse managers and explaining the rationale for the study. It was arranged with the managers that the investigator would provide verbal and/or written feedback from the study.

2.5.2 Revised questionnaire response rates

A return rate of 153 questionnaires was achieved for the revised questionnaire, indicating a 34 percent response rate. It is difficult to estimate the return rate because the investigator did not have full control over the distribution of the revised questionnaire to all participants. The investigator visited nursing staff groups within the three local mental health services and could make an accurate estimate for nurses response rates. However, the investigator distributed the revised questionnaires to clinical psychologist's via their regional P.S.I.G.E. convenor. A majority of the convenors asked for a specific number of questionnaires to be sent, while others requested enough questionnaires for an

estimated number of clinical psychologist's within their regional group. Therefore it was impossible to determine whether all questionnaires distributed in this way reached potential participants. The response rates therefore are based on estimated numbers.

2.5.3 Test re-test

A second mail-shot of the revised questionnaire and vignette was sent to a subgroup of participants in order to assess test re-test reliability. This was carried out when 184 of the completed revised questionnaires were returned. A majority of participants offered to be re-contacted for the second part of the study ($n=123$), indicating 67 percent. These participants would have completed the original questionnaire between two to eight months previously. A randomised numbers table (Blalock, 1972) was used to select those participants who provided their addresses and opted into the second stage of the study. Less than one hundred ($n=81$) test re-test questionnaires were distributed. Amendments were made to the information sheet (appendix 5) and to part 5 of the questionnaire which requested demographic details (appendix 6). The instructions sheet and parts 1-4 of the questionnaire remained the same as before. A stamped addressed envelope was enclosed.

Some studies who have employed the Theory of Planned Behaviour have not used a test-retest methodology which weakens the results of their studies (Beale & Manstead, 1991; Conner *et al.*, 1996; Reinecke *et al.*, 1996; Terry & O'Leary, 1995; Traeen & Nordlund, 1993). The current study aimed to address this potential weakness.

2.6 ETHICAL APPROVAL

Ethical approval was sought from the three local research ethics committees covering the three mental health services that the qualified nurse participants and local clinical psychologists worked in. Approval was granted by all three committees (appendix 7).

Participants (namely, clinical psychologists belonging to the National P.S.I.G.E. groups) not covered by the auspices of an ethics committee were treated in exactly the same way as the nurses and the same guidelines for obtaining consent were observed. The National P.S.I.G.E. were approached prior to local P.S.I.G.E. groups for approval. Consent was also obtained from the appropriate Managers of each local older adult mental health service. This involved written correspondence and visits explaining the rationale and procedure of the study.

2.7 DATA ANALYSIS

The main statistical analysis was a within group multiple-regression. The direct and indirect measures for the main components of the theory were correlated with a behavioural intention measure. Anxiety was correlated alongside the components of the theory with a behavioural intention measure. Chi-squared and Mann-Whitney tests investigated the differences on other factors between groups. A between group comparison of clinical psychologists and nurses was also used.

2.8 DISSEMINATION OF RESULTS

Participants who completed questionnaires will receive information concerning the results and implications of this study. For nurses, a two page summary will be distributed to those who indicated an interest, and will be forwarded to Managers. For clinical psychologists, the two page summary will also be available. In addition, a summary article concerning the research will be published in the P.S.I.G.E. Newsletter and a journal concerned with mental health issues for older adults. Presentations are also planned for units involved with the study and professional groups.

Section 3

RESULTS

3.0 RESULTS

This section presents the following results:

- response rates for the pilot and revised questionnaires, and for the questionnaire sent to a subgroup of participants to assess re-test statistics,
- demographic details of the participants,
- internal reliability of the revised questionnaire,
- explicit testing of the hypotheses,
- the test re-test reliability,
- descriptive data,
- comments from participants, and
- a brief summary of the hypotheses confirmed or unconfirmed.

All statistical analyses were performed using SPSS for Windows (SPSS, 1992)

3.1 RESPONSE RATES

3.1.1 Questionnaire response rate

A total of 13 nurses and 18 clinical psychologist completed the revised questionnaire in the pilot stage ($n=31$) as mentioned in the Method (section 2.4.2). A total of 44 nurses and 109 clinical psychologists provided completed revised questionnaires in the main study ($n=153$). The total possible participant response rate is estimated at approximately 450 in the main study, indicating a 34 percent response rate for the revised questionnaire (see Table 6). This estimated response rate is slightly above the average expected of 30 percent for questionnaire studies (see Introduction section 1.2.5).

Table 6: Response rates for revised questionnaire in the main study

Distribution to:	Total No.	Response Rate
Nursing Staff	150	44
Clinical Psychologists	300	109

Overall, the total number of data sets used for the statistical analyses will be from 184 participants. This consists of 31 revised questionnaires returned during the pilot stage, and 153 revised questionnaires returned for the main study. The questionnaires used in the pilot and main study were identical in design and layout. The combined response rates for 31 pilot questionnaires received out of 36 distributed, and 153 revised questionnaires out of 450 distributed is 38 percent (total n=184). This suggests a good response rate.

3.1.2 Test-retest questionnaire response rate

A total of ten nurses and 19 clinical psychologists provided a completed revised questionnaire sent out for a second time as part of the main study in order to assess test re-test reliability (n=29). The total sample forwarded the test re-test questionnaire was 81, indicating a 36 percent response rate to this second request (see Table 7).

Table 7: Response rates for re-test questionnaire

Distribution to:	Total No.	Response Rate
Nursing Staff	28	10
Clinical Psychologists	53	19

Of the nursing staff who returned the re-test questionnaires ($n=29$), nine were female and one male. Of the clinical psychologist group who returned completed revised questionnaires, 13 were female and six were male. See section 3.6 for test re-test analyses.

3.2 DEMOGRAPHIC DETAILS

Of the total sample who completed questionnaires in the pilot and main study stages ($n=184$), the majority were female ($n=127$), clinical psychologists ($n=127$). An equal number of participants worked with older adults with functional and organic difficulties ($n=92$ per group). The average length of time the participants had been qualified was just over ten and a half years (mean=10.56years; $SD=7.87$; range=6months to 40years). The average length of time participants had worked with older adults with progressive memory problems was just over seven and a half years (mean=7.84years; $SD=5.84$; range=6months to 27years). Of the total sample the majority worked in the community ($n=98$), which accounted for 53 percent. The minority worked primarily within hospital or ward settings ($n=86$) and accounted for 47 percent.

3.3 INTERNAL RELIABILITY OF THE REVISED QUESTIONNAIRE

Cronbach alpha coefficient tests were carried with the pilot questionnaire responses and those in the main study to assess internal reliability. As indicated in the Method (section 2.3.6) a mean alpha value of .87 was obtained ($n=31$) for the draft questionnaire responses in the pilot stage. This indicated that the draft questionnaire was sufficiently reliable to continue with the main study. The mean Cronbach alpha value was .86 for 184 participant responses to the revised questionnaire. This indicates a slight decrease in the internal reliability of the main study questionnaires when compared to the pilot questionnaires. As mentioned in the Introduction (section 1.2.6) other studies have obtained mean alpha values of between .77 to .87 (Ajzen & Madden, 1986; Terry &

O'Leary, 1995). The alpha values for each part of the revised questionnaire (i.e. theory and anxiety components) are presented in Table 8. As such, alpha values were calculated for the direct and indirect measures comprising attitude, subjective norm, and perceived behavioural control. The two items assessing anxiety were also assessed for internal reliability.

Table 8: Cronbach alpha values for each part of the revised questionnaire in the main study

Components	Alpha values	Number of items
Direct attitude	.71	6
Indirect attitude	.61	18
Direct subjective norm	.80	2
Indirect subjective norm	.85	14
Direct perceived behavioural control	.65	4
Indirect perceived behavioural control	.78	18
Anxiety	.86	2

Table 8 indicates that the alpha values range between .61 to .86 for the different sections of the questionnaire. The mean alpha value obtained in this study was consistent with other studies and indicate satisfactory levels of internal reliability.

3.4 ANALYSES IN RELATION TO THE RESEARCH HYPOTHESES

3.4.1 Hypothesis 1

Health professionals regularly discuss (i.e. at least once a month) with older adults the implications of their progressive memory problems (dementia).

This hypothesis will be assessed using three of the items on the questionnaire, and by summarising test re-test analyses. These are presented below.

3.4.1.1 Frequency of discussing dementia

The three items assessed to investigate frequency of discussing dementia are as follows. The first two items concern behavioural intention: one is a global question which asks participants how likely they are to discuss such matters with older adults during the next month and uses a semantic-differential scale (see Table 9); and the other is related to a vignette asking participants what they would do in that specific situation (see Table 10). The third item is the question where participants indicate a self-assessment of past behaviour (see Table 11).

Table 9: Frequency and percentages for the first behavioural intention item (global question)

Scale labels	Frequency	Percentages
Extremely unlikely	5	3
Quite unlikely	13	7
Slightly unlikely	14	8
Neither likely or unlikely	18	10
Slightly likely	30	16
Quite likely	48	26
Extremely likely	56	30

Table 9 indicates that the most frequent response for the first behavioural intention item (that is, a global assessment of behavioural intention) was the scale option labelled 'extremely likely'. This obtained 30 percent of all responses, and suggests that about a third of participants predicted that they would be extremely likely during the next month to discuss with older adults the implications of their progressive memory problems. Overall, 72 percent of participants indicated that they would be likely to discuss such matters. However, nearly 20 percent of participants indicated that they would be unlikely to discuss matters with their clients, and ten percent were neutral.

Table 10: Frequency and percentages for the second behavioural intention item (vignette)

Scale labels	Frequency	Percentages
Extremely unlikely	6	3
Quite unlikely	5	3
Slightly unlikely	6	3
Neither likely nor unlikely	16	9
Slightly likely	39	21
Quite likely	60	33
Extremely likely	52	28

Table 10 indicates that the most frequent response for the second behavioural intention item related to the vignette was 'quite likely', which obtained 33 percent of all responses. The 'extremely likely' option obtained slightly less at 28 percent of all responses. These frequencies suggest that 82 percent of participants predict that they would be likely to talk to Mrs Smith (woman in vignette) about the implications of her progressive memory problems. Participants appear to be more likely to discuss matters with Mrs Smith rather than with older adults with whom they work. Less than ten

percent of participants provided a response indicating that they would be unlikely to discuss such matters, and nine percent were neutral.

Table 11: Frequency and percentages for the self-assessment of past behaviour item

Scale labels	Frequency	Percentages
Not at all	26	14
Between 1-3 times	87	47
Between 4-6 times	42	23
Between 7-9 times	14	8
10 times or more	15	8

Table 11 indicates that the most frequent response to the self-assessment of past behaviour was the option of between one to three times that participants. This indicated that participants estimated that they had discussed dementia with older adults between one to three times in the past month. This category obtained 47 percent of all responses. These results indicate that, for nearly half the participants, the frequency of discussing such matters with clients is estimated as between one to three times per month. Only 14 percent of participants indicated that they had not discussed such matters with their clients. These results will be discussed further in the Discussion (section 4.3.1).

To summarise, it seems that participants are in favour of deciding to discuss with older adults the implications of their dementia at least once a month. Participants self-reported that they are slightly less likely to discuss such matters with the older adults with whom they work than is suggested by responses to the example used in the vignette. In addition, nearly half of the group estimated they had discussed such matters between one to three times in the previous month.

3.4.1.2 Test re-test reliability

The revised questionnaire was completed by 29 participants for a second time, between two to eight months after the original questionnaire had been completed. Wilcoxon two-related samples t-tests compared the means of each questionnaire completed at different time points and assessed for significant differences between ratings over time. The results indicating significant differences at the two points of completion ($p<.001$, 2-tailed) are presented in Table 12.

Table 12: Summary of test re-test analyses

Items	Significance values
Good vs bad (direct, attitude)	.038
How likely am I to have the time to spend talking with older adults (indirect, perceived behavioural control)	.045

The analyses indicated that there were two significant values in the data. That is, two pairs of items were significantly unreliable out of the total number of 69 pairs compared. These include a significant difference for one item making up the direct attitude measure, which asked whether health professionals thought that discussing matters with older adults is good or bad. The second significantly unreliable item was a belief about how likely participants would be to have the time to spend talking with older adults. The other 67 pairs assessed reached non-significant levels of $p>.05$.

Approximately three items could be expected to be significant due to chance. To summarise, these results indicate that the participant responses' were similar when completed at different time points and the questionnaire is thus reliable at test re-test.

Thus, the results indicate that hypothesis one is confirmed. It seems that most participants indicated that they would be likely to decide to discuss the implications of dementia with older adults over the next month (at least once a month). Test re-test analyses indicate that generally these responses seem to remain stable over time.

3.4.2 Hypotheses 2-4

Analyses in response to research hypotheses two, three and four will be presented together. One stepwise multiple regression was used to assess the relative predictive qualities of the Theory of Planned Behaviour components. The results responding to the three hypotheses will be summarised following the regression analysis in section 3.4.2.2

- H2:** There will be an association between behavioural intention and attitude, that is, the degree to which health professionals view discussing with older adults the implications of progressive memory problems in a positive way will predict their behaviour.
- H3:** There will be an association between behavioural intention and subjective norm, that is, the degree to which health professionals are influenced by other people's views about discussing this with older adults in a positive way will predict their behaviour.
- H4:** There will be an association between behavioural intention and perceived behavioural control, that is, the degree to which health professionals consider they have control over discussing this with older adults will predict their behaviour.

3.4.2.1 Analyses concerning Hypotheses 2-4

One stepwise multiple regression was used to ascertain the factors in the Theory of Planned Behaviour which may account for a proportion of the variability in health professionals' decisions to discuss with older adults the implications of their dementia. In the regression analysis, the dependent variable is the first behavioural intention item. This item was used because it is similar to behavioural intention items used in other studies, and the use of a vignette is less frequently employed. Independent variables entered into the regression were direct and indirect measures for attitude, subjective norm, and perceived behavioural control. The results of the regression analysis are summarised in Table 13.

Table 13: Summary of a multiple regression showing independent variables (related to the theory) that explain significant amounts of the variance in the first behavioural intention measure

Dependent Variable	Independent variables entered into stepwise regression equation that were significant	B	T	R Square	d.f.	F
Behavioural intention	1. Direct subjective norm	0.25	5.09***	0.12	1,182	25.92***
	2. Indirect perceived behavioural control	0.22	3.40***	0.18	2,181	19.49***
	3. Direct perceived behavioural control	0.09	2.82**	0.21	3,180	16.15**

** - $p < .01$, *** - $p < .001$

The multiple regression provided a summary of the variables that explained a significant proportion of the variability of the participants' behavioural intentions. In this regression analysis, the direct subjective norm variable was shown to be the most strongly related to the behavioural intention of participants', with a t value of 5.09 ($p < .001$). This measure alone accounted for 12 percent of the variance. The indirect perceived behavioural control measure was also shown to relate significantly to the

behavioural intention score ($t=3.40, p<.001$), although less strongly than the direct subjective norm measure. Together these two variables explained 18 percent of the variance of the behavioural intention of participants. In addition, the direct perceived behavioural control measure was shown to relate significantly to the behavioural intention score ($t=2.82, p<.01$), although less strongly than the direct subjective norm or indirect perceived behavioural control measure. Altogether these three measures from the Theory of Planned Behaviour explained 21 percent of the variance of the behavioural intention score.

Strictly speaking the statistical analysis employed, that is, a multiple regression, should be used only with interval level data. This study uses predominantly semantic-differential scales which provide ordinal level data (Method section 2.3.2). The investigator is aware that ordinal level data is not ideal for multiple regression analyses, however in the absence of any alternative statistics for ordinal level data, the investigator has chosen to use multiple regression statistics. In addition, the original studies used to confirm and develop the theory employed multiple regressions (i.e. Ajzen & Madden, 1986; Schifter & Ajzen, 1985). However, post-test analyses did not support a key assumption underlying the use of multiple regression, and post-tests indicated that the data is not normally distributed (see appendix 8). To summarise these briefly, the regression was not confirmed by post-test analyses, and it is still appropriate to treat the results with some caution.

3.4.2.2 Summary of results investigating Hypotheses 2-4

As indicated above in response to hypothesis two, neither the direct nor indirect attitude variables significantly influenced the degree to which health professionals discussed with older adults the implications of their progressive memory problems. Thus, hypothesis

two is not supported because attitude was not found to be significantly predictive of participants' behavioural intentions.

In response to research hypothesis three, the direct subjective norm measure was the most predictive independent variable of the degree to which participants are influenced by other people's views about discussing with older adults the implications of their dementia. The direct subjective norm variable explained most of the variance, and the indirect variables were not significantly predictive. Thus, hypothesis three is confirmed in that the direct subjective norm variables explained a significant proportion of the variance in behavioural intention.

Finally, in response to hypothesis four, both the direct and indirect perceived behavioural control measures significantly influenced the degree to which participants discussed with older adults the implications of their dementia. The indirect perceived behavioural control measure was the second most predictive, and, along with the direct subjective norm measure, explained 17 percent of the variance of participants' behavioural intentions. The indirect perceived behavioural control measure also significantly predicted participants' behavioural intentions, although less strongly than the other two. Thus, hypothesis four is confirmed in that both the direct and indirect perceived behavioural control measures contributed to explain a significant proportion of the variance.

Overall, the results indicated that 21 percent of the variance is explained by the Theory of Planned Behaviour. This can be compared with other studies using the theory which have illustrated significant explanations of the variance, ranging from 20 to 68 percent (Ajzen & Madden, 1986; Traeen & Nordlund, 1993; Parker *et al.*, 1995). Therefore, the percentage explained by the theory in this study falls towards the lower

end of the range explained by published articles. The theory can be considered moderately useful when exploring whether or not health professionals chose to discuss with older adults the implications of their dementia.

3.4.2.3 Tests investigating differences between groups

There were no significant differences found between the frequencies of gender and type of difficulty the older adults have (organically versus functionally-ill) between the professions. These results are presented in appendix 9.

3.4.3 Hypothesis 5

The degree to which the 'behaviour' is considered anxiety provoking will be negatively associated with intention to perform the behaviour (that is, perceived behavioural intention). As such, if a health professional is anxious about discussing with older adults the implications of their progressive memory problems, the professional is less likely to have a intention to discuss such matters

A second stepwise multiple regression was used to ascertain whether anxiety accounted for a proportion of the variability associated with deciding to discuss with older adults the implications of their dementia. The dependent variable was the first behavioural intention item. Independent variables entered into the regression were direct and indirect measures for attitude, subjective norm, and perceived behavioural control, and a summation of the two anxiety items. The results of the regression analyses are presented in Table 14.

Table 14: Summary of a multiple regression showing independent variables, including anxiety, that explain significant amounts of the variance in the first behavioural intention measure

Dependent Variable	Independent variables entered into stepwise regression equation that were significant	B	T	R Square	d.f.	F
Behavioural intention	1. <i>Direct subjective norm</i>	0.25	5.09***	0.12	1,182	25.92***
	2. <i>Anxiety</i>	-0.16	-4.12***	0.20	2,181	22.59***
	3. <i>Indirect perceived behavioural control</i>	0.01	2.79**	0.23	3,180	18.22**

** - $p<.01$, *** - $p<.001$

In this analysis, the direct subjective norm variable was shown to be most strongly related to the behavioural intention of participants. As in the previous regression (section 3.5.2), this measure alone accounted for 12 percent of the variance (R Square=.12, d.f.=1,182, $p<.001$). The anxiety measure was shown to relate significantly (negatively) to the behavioural intention score, although it explained less of the variance in than subjective norm ($t=-4.12$, $p<.001$). Together these two variables explained 20 percent of the variance of the behavioural intention score (R Square=.20, d.f.=2,181, $p<.001$). Finally, the indirect perceived behavioural control measure was significantly related to participants' behavioural intention scores. This measure, along with the other two, explained 23 percent of the variance at the $p<.01$ level (R Square=.23, d.f.=3,180, $p<.01$). Therefore, the indirect perceived behavioural control measure also explained a significant proportion of the variance in behavioural intention. In order to achieve full statistical rigour, post-tests were employed following the regression to see if the data was normally distributed. Post-tests indicated that the data was not normally distributed (see appendix 9). Thus, the regression was not confirmed, and it is therefore appropriate to treat the results with some caution.

To summarise, there is evidence to support hypothesis four. The degree to which talking to older adults about dementia was considered anxiety provoking was negatively associated with participants behavioural intention. As such, if participants predicted they would be anxious when talking to older adults about dementia, then they would be less likely to do so.

3.4.4 Other areas investigated

3.4.4.1 Comparison of the means of each professional group

The means differences between each professional group will influence the results.

The total sample was large enough to warrant a group comparison of each profession. One sample Kolmogorov-Smirnov Goodness of Fit tests (non-parametric) were used in order to assess whether the two behavioural intention items (global item and vignette), and the self-report of past behaviour data were normally distributed in each of the two professional groups. The results for the first behavioural intention item are reported below (section 3.4.4.2). The results indicate that the second behavioural intention item (vignette) and the self-report of past behaviour item did not have a normal distribution of responses in each of the professions. The results of the tests are presented in appendix 10.

Thus, Mann-Whitney tests were used to investigate any differences between the professions for these two items. A non-significant result was obtained with a Mann-Whitney test for the second behavioural intention item (vignette) at the $p > .05$ level ($p = .45_{ns}$, 2-tailed). A significant result was obtained for the estimation of past behaviour item at the $p < .05$ level ($p = .00$, 2-tailed). These results indicate that there are no differences in responses to the second behavioural intention item between the

professions, and there are differences in responses to the past behaviour item between the professions. It appeared that nurse participants had discussed dementia with their clients more than clinical psychologists. Thus, some evidence was found to suggest that a difference existed between self-reported past behaviour of nurses and that of clinical psychologists.

3.4.4.2 Profession

Profession will influence the results, for example, a difference will exist between the behavioural intentions and beliefs of nurses and those of clinical psychologists'.

A Mann-Whitney test was used to investigate any differences between the professions for the first behavioural intention item, as Kolmogorov-Smirnov tests indicated that the data was not normally distributed concerning profession (appendix 10). A non-significant result was obtained with a Mann-Whitney test at the $p > .05$ level ($p = .35_{ns}$, 2-tailed). The results indicate that there are no differences in responses between the professions. Thus, no evidence was found to suggest that a significant difference existed between the behavioural intention of nurses and that of clinical psychologists.

3.4.4.3 Gender

Gender of the health professional will influence the results.

One sample Kolmogorov-Smirnov Goodness of Fit tests (non-parametric) indicated that the first behavioural intention item (global question) did not have a normal distribution of responses in each of the sexes (appendix 10). Therefore, a Mann-Whitney test was used to investigate any differences between the sexes. A non-significant result was obtained from the Mann-Whitney test at a $p > .05$ level ($p = .56_{ns}$, 2-tailed). The results indicate that

there are no differences in responses to this behavioural intention item (global question) between the sexes. Thus, no evidence was found to suggest that a significant difference existed between the behavioural intentions of men and that of women.

3.4.4.4 Length of time worked with older adults

The length of time health professionals have worked with older adults will influence the results.

A bivariate correlation was used (non-parametric) to assess whether participants' experience influenced their behavioural intention scores. Three correlations were made with the behavioural intention score, these were with the length of time participants had been qualified, the length of time they had worked with older adults in mental health settings, and the length of time they had worked with older adults with progressive memory problems. The estimation of experience was rounded up to the nearest six month. The results are presented in Table 15.

Table 15: Results of correlations between behavioural intention and length of experience

Experience	Mean	SD	Significance values
Length of time qualified	10.55	7.87	0.10
Length of time worked with older adults in mental health services	7.60	5.66	0.22*
Length of time worked with older adults with dementia	7.84	5.84	0.23*

* - $p < .01$, 2-tailed

Table 16 indicates that there was a significant correlation ($p < .01$, 2-tailed) between participants' behavioural intentions and the length of time they had worked both in mental health services with older adults, and worked with older adults with progressive memory problems. Thus, the more experience participants had of both working in mental health services with older adults, and of working with older adults with dementia, the more likely they were to discuss with clients the implications of their dementia. Thus, it seems that the more experience participants had of working with older adults, the more likely they were to chose to discuss with their clients the implications of dementia.

3.5 COMMENTS FROM PARTICIPANTS

A space was provided for participants to write their comments about the questionnaire at the end of part 5. Of the total sample ($n=184$), 82 participants wrote comments, accounting for 45 percent of the group. A qualitative analysis was not carried out on this data as this was not the main remit of this research. However, two comments are presented below which represent polar views about the topic.

Participant number two, a female nurse with 15 years experience of working with older adults with dementia:

I feel very strongly that many carers and close relatives need more help to accept the diagnosis and to understand what it means ... I would say that literature on dementia and support groups and one to one talks with the carers would bear more fruit and make life more acceptable all round than trying to talk to a patient with memory loss about their illness.

Participant number 98, a female clinical psychologist with six and a half years experience of working with older adults with dementia:

I always try to give feedback to clients following an assessment, including for dementia. I would go into as much detail about the results and possible contributing factors as I felt the client wanted, including further deterioration and coping strategies. ... I do not use the word 'dementia' to the referred person ... I talk about memory problems, changes in abilities etc. but only use the term dementia to carers/family ... If a client were to ask 'Do you mean I have dementia?' I would answer honestly.

3.6 SUMMARY

Hypothesis one was supported by the results, as participants reported they intended to regularly talk (that is, at least once a month) to older adults they work with about the implications of their progressive memory problems. A third of the participants indicated that they would be 'extremely likely' to discuss with their clients the implications of dementia. Nearly half of the participants indicated that over the previous month they had discussed such matters between one to three times. Three measures significantly influenced participants' behavioural intentions. These were, in descending order, the direct subjective norm measure, anxiety and the indirect perceived behavioural control measure. The Theory of Planned Behaviour appeared to be a moderately useful model to investigate the subject matter of this study, in comparison to other studies. Studies which have used this theory have achieved significant explanations of the variance, in behavioural intention and/or behaviour, ranging from 20 to 68 percent for the three main components of the theory (Ajzen & Madden, 1986; Traeen & Nordlund, 1993; Parker *et al.*, 1995). Therefore, this study falls towards the lower range of significant explanations of the variance of behavioural intention. Overall, the theory and anxiety components explained 23 percent of the variance.

Hypothesis two, three, and four were supported by the results. As such, if participants viewed other peoples' views in a positive way concerning discussing dementia with older adults, it predicted their behaviour. The degree to which participants consider they have full control when discussing with older adults the implications of dementia predicted their behavioural intention to discuss such matters. Finally, participants would be less likely to discuss such matters if they were anxious about doing so. Hypothesis two was not confirmed by the results, as participants' attitudes did not significantly influence their intentions to discuss such matters with older adults.

Other variables investigated included the affect gender, profession and the length of time participants had worked with older adults had upon their behavioural intentions. Neither gender nor profession had a significant effect upon behavioural intention, although length of experience did. A comparison of the means of each professional group indicated no differences existed for both behavioural intention items between professions. However, a difference did exist between responses for the past behaviour item between professions. The implications of all these results are discussed in more depth in the next section.

4.0 DISCUSSION

This section presents the following:

- a brief summary of the research findings,
- methodological considerations,
- interpretation of the results related to the research questions and hypotheses,
- clinical and service implications, and
- future research suggested by this study.

4.1 SUMMARY OF RESEARCH FINDINGS

4.1.1. Psychometric properties of the revised questionnaire

This section discusses briefly whether the revised questionnaire achieved adequate reliability. First, Cronbach alpha coefficient tests indicated that the revised questionnaire achieved satisfactory internal reliability, and its' internal reliability is consistent with other studies (Ajzen & Madden, 1986; Terry & O'Leary, 1995). Secondly, Wilcoxon two-related samples t-tests indicated that participant responses' were similar when completed at different time points and the questionnaire is thus reliable at test re-test.

4.1.2 Summary of investigations of the research questions and hypotheses

A summary of the investigations presented in the Results section will be provided briefly here, and interpretations of these will be discussed in more detail in section 4.3. Data from 184 health professionals working with older adults with dementia highlighted that nearly three quarters of the sample would be likely to discuss with older adults the implications of their dementia. Less than a quarter indicated that they would be unlikely to do so. In assessing past behaviour, few participants indicated they had not discussed dementia with their clients over the past month, whereas, nearly half indicated that they

had done so between one to three times during a one month period. This could be considered a low frequency, however there are no published studies with which to compare this with (for further discussion see section 4.3.1). These results indicated that participants discuss such matters more frequently than perhaps medical staff appear to inform patients about a diagnosis of dementia (Rice & Warner, 1994; Wolff *et al.*, 1995).

The results of the second multiple regression analysis indicated that the relative importance of the Theory of Planned Behaviour and the anxiety components related to behavioural intention were in descending order: subjective norm, anxiety, and perceived behavioural control. Altogether the components of the theory, analysed in the first multiple regression, explained 21 percent of the variance in the behavioural intention scores. Anxiety also accounted for eight percent of the variance in behavioural intention illustrated in the second multiple regression. Comparing the current study to the study by Raats and colleagues (Raats *et al.*, 1995), who used an additional component along with the theory, the additional anxiety component in this study explained more of the proportion of the variance. Previous studies investigating particular behaviours have found that the main components of the Theory of Planned Behaviour explain significant amounts of the variance in behavioural intention and/or behaviour, ranging from 20 to 68 percent (Ajzen & Madden, 1986; Traeen & Nordlund, 1993; Parker *et al.*, 1995). The study found that 21 percent of the variance was explained exclusively by the theory (in the first regression analysis) which falls towards the lower end of the range when compared to other published studies. Although the percentage explained by the theory is not large, in the absence of other appropriate theories, this theory was considered moderately useful to investigate this subject matter (see section 4.3.6).

Attitude, gender and profession did not contribute significantly to participants' behavioural intentions to discuss with older adults the implications of their dementia.

Gender and profession also did not suggest that a difference existed in their predicted responses to behavioural intention between men and women, or nurses' and clinical psychologists' behaviour. Although, evidence was found to suggest that a significant difference existed between the self-report of past behaviour of nurses and that of clinical psychologists. It appeared that nurses had discussed dementia with their clients more often than clinical psychologists. Finally, the length of participants' experience was associated with participants' behavioural intentions. If participants were experienced in both working with older adults in mental health services, and working with older adults with dementia, they were more likely to discuss such matters with their clients.

4.2 METHODOLOGICAL CONSIDERATIONS

There were several limitations to this study. Firstly, this study did not directly observe or assess behaviour. Secondly, although the sample seemed to provide a range of professionals, gender, and experience, a comparison of the professional groups have lead to problems with regional variations. Finally, the design of the study may also have been problematic. These problems will be discussed below.

4.2.1 The measure

A limit of this, and of some existing studies using the Theory of Planned Behaviour, is that the specified behaviour is not directly observed. It was difficult to observe behaviour within the remit of this study. Therefore a limitation of this study is that it involves a correlation of participants' predictions of their behaviour (i.e. behavioural intention) rather than direct observation of their behaviour. Self-reports of behavioural intention may be unreliable and not correlate well with actual behaviour. Despite this there is a substantial body of evidence to suggest that if studies using the Theory of Planned Behaviour specify the time and context closely, behavioural intention is closely related to actual behaviour (Ajzen 1985, 1988; Ajzen & Madden, 1986).

4.2.3 A disparity was illustrated between two items assessing participants' self-reported intentions to discuss with older adults the implications of their dementia. It seems that they were slightly less likely to discuss matters with the older adults with whom they work than is suggested by responses to the example used in the vignette. The frequencies of discussing such matters with Mrs Smith (in the vignette) were slightly higher than those for discussing matters with clients.

Possible explanations of this disparity between participants' own clients and a vignette will be explored briefly. Participants may be more likely to discuss the implications of Mrs Smith's dementia (woman in vignette) with her because they avoided the reality of the situation presented in the vignette. For example, participants may not have perceived Mrs Smith as real person, with a real history, and concerned carers. Alternatively professionals may have read more into the vignette than was stated, and differences may exist between participants' understanding of the vignette. Another possible explanation is that participants may have intended to discuss dementia with Mrs Smith because the vignette implied that she had a diagnosis of mild dementia. The sentence 'overall her symptoms appear typical of mild dementia' in the vignette may have increased the likelihood that participants' would discuss dementia with her as they believe that it is appropriate to inform a sufferer in the early stages of their disease. Previous research has indicated that some health professionals hold this view, and are more likely to inform sufferers about their diagnosis if they are in the early stages of dementia (Rice & Warner, 1994). Overall, the disparity between the two items is not marked and indicates that generally the majority of participants intended to discuss such matters.

4.2.2 The sample

A comparison of a national group of clinical psychologists with a local group of nurses may involve regional variations. This study found no evidence to suggest that a significant difference existed between the behavioural intention of men and women, nor of nurses and clinical psychologists. Some evidence was found to suggest that a difference existed between the self-reported past behaviour of nurses and that of clinical psychologists. It appeared that nurse participants had discussed dementia with their clients more than clinical psychologists. Also, the more experience participants had of both working in mental health services with older adults, and of working with older adults with dementia, the more likely they were to discuss with clients the implications of their dementia.

However, of the sample who completed questionnaires ($n=184$) the participants appeared representative of the two professional groups. Both nursing and clinical psychology are female dominated professions. The sample also provided an equal number of participants who worked predominantly with older adults with functionally and organically-based difficulties ($n=92$ per group). The majority of participants were clinical psychologists (69 percent) which may be because twice as many questionnaires were distributed to this profession. There was also a wide range of experience as qualified professionals, ranging from six months to 40 years, and of experience of working with older adults with organically-based problems, ranging from six to 27 years. Finally, the sample provided nearly an equal percentage of those who worked in the community (53 percent) and those who worked primarily within hospital or ward settings (47 percent).

The response rates to all three stages of the study were satisfactory and comparable to other postal questionnaire surveys (Black & Champion, 1976; Goyder,

1985; Labovitz & Hagedorn, 1971; Meyers & Grossen, 1974). The combined response rate for the pilot and main study stages was 38 percent, and 36 percent returned the test re-test questionnaire. However, the current study did not use the general population of nurses and clinical psychologists. It could be argued that the attrition rate (62 percent) was affected by those individuals who disagreed with talking to older adults about the implications of their dementia. These individuals may have chosen not to participate on the assumption that they needed to discuss dementia with their clients in order to complete the questionnaire. However, there is no evidence of a response bias.

4.2.3 Design

It is possible that participants were biased towards providing socially desirable responses. Thus, participants may have tended to provide responses which were in favour of choosing to discuss with older adults the implications of their dementia. This issue of social desirability was difficult to address, however limited information was provided about the study and about previous research in the information sheet (Method section 2.3.3). This aimed to encourage participants to share their views based on their experience.

4.3 INTERPRETATION OF RESEARCH FINDINGS

This study indicates that most health professionals who participated in this study discussed with older adults the implications of their dementia. What influences health professionals to choose whether or not to discuss such matters with clients is less clear. This study indicates that subjective norm, anxiety and perceived behavioural control are particularly important in participants' decisions. These will be discussed further below.

4.3.1 Frequency of discussing dementia with older adults

The proposal in hypothesis one that a regular discussion about dementia with clients was 'at least once a month' was based on experience of working in clinical settings. Previous literature has not investigated how often nurses and clinical psychologists discuss with older adults the implications of their dementia. Nurses and clinical psychologists were also consulted about this matter, alongside the research supervisors. The frequency chosen should be treated with caution as the experience of those consulted concerning frequency may be atypical to a majority of other professionals.

The results of this study indicate that participants discussed dementia with their clients more frequently than medical staff appear to inform patients about a diagnosis of dementia (Rice & Warner, 1994; Wolff *et al.*, 1995). It is difficult to interpret the results of this study due to the limited research into this area. Broad comparisons with studies investigating diagnosis are made tentatively and yet appear relevant. Overall, this study indicates that such discussions most frequently occur between one to three times over one month.

Factors such as, amount and/or nature of workload, may influence this estimation. For example, health professionals working exclusively in mental health services for older adults are more likely to encounter more opportunities to discuss dementia with clients than perhaps general practitioners who work with patients from the general population. Therefore it could be expected that professionals who work in mental health services would be more likely to have increased opportunities to discuss dementia with clients. However, variations may exist even between the practice of professionals working in mental health services. As such, mental health professionals may work exclusively with clients with dementia (i.e. on a ward for organically-ill patients) or with clients who have both organically and functionally-based illnesses (i.e. community work).

This study indicates that some health professionals have discussed with older adults the implications of their progressive memory problems. This appears to contradict other studies where health professionals, namely general practitioners and Consultant Psychiatrists, tend not to discuss with sufferers their diagnoses and prognoses (Rice & Warner, 1994; Wolff *et al.*, 1995). Phillips outlines anecdotal accounts of carers who have openly discussed the diagnosis with the sufferer, and the carers have suggested that this has invariably been helpful and beneficial (1996). Most found that their anxieties about the reaction of the sufferer to the news were unfounded and few expressed regrets at being open with their relatives. Giving emotional support as well as practical advice concerning plans for the future could follow discussions of dementia with patients as necessary.

This study suggests that a majority of those who participated intended to discuss dementia with their clients. However, it is not possible to generalise to other health professionals and assume they hold the same beliefs and intentions. Overall, studies published to date indicate that Consultant Psychiatrists and general practitioners tend not to discuss matters with clients themselves, although a majority inform the carers and/or relatives (Brodaty *et al.*, 1990; Phillips, 1996).

It is speculated that when clinicians first began to discuss a diagnosis of cancer with patients, they had no specific training. Discussing such matters with patients may have lead to increased anxiety (Buckman, 1992). However, over the last 20 years, there has been a change in the attitude of health professionals who now prefer to discuss diagnoses of cancer with patients (Novack *et al.*, 1979). Current research does not indicate that the same has happened for health professionals working with older adults with dementia. The benefits of early identification of dementia, diagnosis and discussion of prognosis could allow for older adults and their families to mobilise a response

(Canadian Task Force, 1991). Older adults may then be able to access appropriate services, or consider moving to a more protective environment. Perhaps increased discussions with clients who have dementia would promote training and reduce anxiety surrounding the difficulty of discussing matters with the client him/herself.

4.3.2 Subjective Norm: the implications of organisational culture

The results imply that the subjective norm measure was the most predictive independent variable in behavioural intention. This implies that if participants perceived others are likely to discuss dementia with their clients, then they would also be more likely to. This would suggest that staff culture change could be a key issue in promoting the discussion of dementia with clients in those cultures not favourable to doing so.

Past research has investigated organisational cultures (i.e. Coopey, 1989).

Coopey broadly defines culture as a knowledge-based guide to acceptable modes of living within a society or a specific social group (1989). Culture is seen as an influence on the way people think and, hence, on their behaviour as they adapt to their social environment (Ekvall, 1989). Culture is also seen as a system of shared meanings which members of a society can use to interpret experience as a guide to behaviour. Rational explanations of events and actions often obscure their deeper meanings which are expressions of shared values and norms. The culture of an organisation helps its members to decide upon courses of action concerning certain situations.

There are two main levels of cultural knowledge: surface knowledge and basic assumptions. Surface knowledge entails that which helps individuals to make sense of social situations and is readily accessible to those who are in the situation (Coopey, 1989). Surface knowledge is embodied in shared beliefs, values and norms that are important for the social group. These beliefs and values provide ways of categorising

events and act accordingly. In psychological terms beliefs are cognitive: individuals believe that certain propositions or statements are true. By contrast, values connect to individuals' feelings about things and reflect modes of responding to situations, of selecting one option rather than another out of all possible actions available. In addition, individuals' beliefs and values need to conform to some extent to the norms of the society's cultural beliefs if s/he is not to become a social outcast.

Secondly, basic assumptions are taken-for-granted theories that, irrespective of individuals' beliefs and values, actually guide the way individuals think and feel (Coopey, 1989). They act as a strong guide to organisational behaviour and there is little deviation from approaches based on assumptions because these assumptions are questioned less often and can be hidden from members of an organisation (Schein, 1985). The development of a strong culture is based on members solving problems according to their beliefs and values. In this way, values are tested and some are confirmed, and assumptions evolve to form the unquestioned basis of daily actions. Suggestions made concerning how to change cultures are presented later in this section.

In relation to dementia, it could be speculated that not informing patients of their diagnosis is a tried and accepted pattern of behaviour among some health professionals. This is likely to be the case, particularly if the task is perceived as challenging and against the social norm. Social influence is said to produce compliance when a target individual publicly conforms to the wishes of an influencing source but does not change his/her private beliefs or attitudes (Brown, 1986). Asch (1958) exemplified this when he investigated compliance in a group situation. This study found that when a single participant was placed among confederates of an experiment and shown lines of different lengths, the average participant conformed to the group consensus on 32 percent of trials. This was found with a group of just three confederates (Asch, 1958). It is not proposed

that health professionals will not discuss dementia with their clients if their colleagues do not do so, because this decision-making process is seen as a more complex one than that. However, Asch's study does imply that social conformity exists in some social situations, and this may be an issue for health professionals when deciding to discuss dementia or not. Indeed, if health professionals are unclear about a diagnosis of dementia, they are probably more likely to decide not to conform to a social norm of not sharing information for two reasons. The diagnosis is unclear and the social norm surrounding it is vague.

4.3.3 Anxiety

A regression analysis indicated that the anxiety component predicted a proportion of the participants' behavioural intentions, although anxiety was less strong than subjective norm. Generally speaking the notion that anxiety leads to avoidance is well established in cognitive psychology (Hawton *et al.*, 1989). Anxiety appears to have restricted some participants from discussing the implications of dementia with their clients. This could imply that some health professionals' require training to become more competent and/or confident. Training could provide guidance for decision-making concerning individual clients. It seems important to assess the impact discussing dementia with the client will have on the client him/herself and on his/her carers. Although some carers may not wish this information to be shared with the sufferer or believe the sufferer would want to be informed (Phillips, 1996). Training may be aided by a team policy concerning steps to aid decision-making, including the wishes of carers, about discussing such matters with older adults.

Other factors may help to reduce health professionals' anxiety about discussing such matters in appropriate cases. For example, it may be helpful to be able to refer the client on to appropriate services, therefore adequate service provision will be required. Having appropriate literature to give to the client about the nature of dementia may also

be useful. For example, a booklet published by the Alzheimer's Disease Society (1996) is clearly written and provides information about the nature of dementia, and organisations to contact for help and advice. Further suggestions about training and other implications will be discussed later (section 4.4).

4.3.4 Perceived behavioural control

The regression analysis indicated that perceived behavioural control predicted a small but significant proportion of the variance. This could imply that, if participants feel in control of potential obstacles to discussing dementia, they are more likely to. Increased perceptions of control may relate to different factors, including the professionals' skills and limits on time. However, further research is required to assess which components may influence increased perceptions of behavioural control.

4.3.5 Alternative explanations of the variance

It seems surprising that attitude did not explain a proportion of the variance in behavioural intention. From a common sense view it would seem likely that participants would need to view discussing dementia with clients as a positive action in order to discuss such matters. However, attitude was not found to be significantly important. This may reflect a belief that, although in essence discussing dementia with clients is perceived as a positive action, some participants felt that the consequences of doing so might be markedly negative. For example, some health professionals may believe that discussing dementia with patients may result in distress for the sufferer. Instead of attitude being important, it seemed that what participants believed others to think about discussing such matters, and their anxiety levels, were more important in predicting their behavioural intentions'.

4.3.5 This study explained nearly a quarter of the variance in behavioural intention responses which indicates that other factors are involved when health professionals decide whether to discuss dementia with clients. One could speculate about other factors which might be involved, for example, details about the clients' history and coping strategies, what the professional thinks about the evidence for a probable diagnosis of dementia, the sufferers' own wishes and level of insight, family requests and mental health team policy, legal restraints (such as, to stop driving), ethical issues, how competent the professional feels about dealing with the possible 'aftermath', and confusion about which profession is responsible for informing the patient.

discussion

4.3.6 The utility of the Theory of Planned Behaviour

As mentioned earlier, the Theory of Planned Behaviour is considered moderately useful when investigating this research subject. It could be argued that the theory did not explain a larger proportion of the variance in behavioural intention for two reasons. First, participants were uncertain how to assess their own behaviour of discussing dementia with clients. Secondly, perhaps this study addressed a new and taboo subject area, by investigating discussions of dementia with clients as opposed to with caregivers. Many participants might have been less able to self-report the components of their decision-making process as a result. Also the behavioural intention concept of 'discussing with older adults the implications of their progressive memory problems' may be less easy to grasp than behaviours (and concepts) used in other studies. Other studies employing the theory have investigated more 'concrete' behaviours, such as dieting (Conner *et al.*, 1996; Raats *et al.*, 1995), exercise (Terry & O'Leary, 1995), and visiting public places to drink alcohol (Traeen & Nordlund, 1993).

employ teaching and learning from individuals both in and outside of a research

4.4 CLINICAL AND SERVICE IMPLICATIONS

In this study, it was not assumed that, by discussing with older adults the implications of their dementia, clients would make any positive changes as there is currently little evidence to support this assumption. Discussing a diagnosis of dementia with the sufferer may prompt the sufferer to make changes, such as, make plans for their future and that of their families, or understand more about the disease, or consent to treatments available. Alternatively, negative changes may occur such as, the sufferer becoming depressed about their illness or misunderstanding the information shared. However, this study provided no evidence to suggest what older adults might do following such a discussion.

The main clinical implication of this study implies a need for training programmes of health professionals about discussing dementia with clients. Most of the participants indicated that they intended to talk to their clients about dementia, however some did not which may reflect that more generally health professionals do not receive training in such matters. In this part of the Discussion, components of training programmes are outlined briefly, and a model of how to break bad news is presented (section 4.4.1). Service implications for promoting good multi-disciplinary team work are also discussed. This study also implies an intervention to change some staff cultures towards considering a more positive view of discussing dementia with older adults. As mentioned earlier, Coopey indicates that organisational culture develops and the beliefs of its members are confirmed (1989). Coopey proposes three ways that cultures can change: the content of cultural knowledge, competition between subcultures, and individual importation of cultural knowledge. An example for this study might be to employ teaching and training from individuals both in and outside of the services.

Components of possible programmes to train health professionals to discuss dementia with clients may include the following components. An individual assessment may be required in order to inform the health professional of possible affects a discussion with the sufferer about dementia may have. A history of the client and his/her coping strategies may prove useful. It may be helpful for the carers to attend the discussion to facilitate and/or back up what professional says. Also, an appropriate environment to talk to older adults is important. However, this may not be possible for some health professionals, for example, nurses working primarily in hospital settings. In addition, health professionals could create a climate in which sufferers and carers feel better able to ask questions without the pressure of time upon them. Finally, it may be helpful to use certain techniques to clarify the information for the sufferer and to prompt their memory of the discussion. For example, an audio-tape of the discussion and information leaflets may prompt the older adults' memory at a later date. It seems appropriate to train and educate health professionals, based on past research, aimed at changing their attitudes about potentially negative consequences from discussing dementia with clients. Some studies indicate that a majority of older adults with and without dementia would want to be told about a diagnosis of dementia (Erde *et al.*, 1988; Wolff *et al.*, 1995). In addition, provisional investigations into the consequences of discussing dementia appear beneficial for the sufferer (Husband, 1996).

As mentioned earlier, some health professionals may not have adequate skills to discuss dementia with clients. A tendency to avoid breaking bad news to patients may often be seen as a lack of sympathy by health professionals, but is often because the professional feels ill-prepared owing to a lack of training either pre or post-registration level (Sablewicz, Kershaw, & Mangan, 1994a). Possible components to promote good multi-disciplinary teamwork within mental health services are outlined.

These components may include a team policy of the procedure of assessing whether an older adult should be informed about their dementia. A thorough assessment should be made to investigate the evidence of a probable diagnosis of dementia. This assessment should also include a view of possible consequences for older adults if information about a diagnosis of dementia is shared with them. In one of the initial interviews a nurse commented that it is harder to discuss such matters with those clients whom the nurse liked better than others. Therefore it might be questioned whether this professional would be the most appropriate person in this case. It may be appropriate to designate a member of the team who knows the older adult well to either talk with the older adult or accompany the Psychiatrist for this purpose. Carers may also be invited to this discussion. It is important that whoever discusses dementia with the client has the skills and information required, or knows how to access appropriate information.

Other possible components to facilitate discussions might involve a multi-disciplinary team sharing their professional views about any evidence of dementia and differences may exist within a team. The team should also communicate with staff working with the patient on a daily basis (i.e. in day hospitals). This will enable staff to know whether a probable diagnosis of dementia has been suggested and therefore how to communicate appropriately with the client. In addition, communication between mental health professionals and other professionals needs to be frequent. Otherwise difficulties may arise, for example, general practitioners might assume the community team has discussed dementia with the client and the team might think the general practitioner has done so.

Finally, it appears useful to have booklets/leaflets available for professionals to educate others about dementia, including clients, relatives and other health professionals. It seems good practice to record what was said, as well as, the reactions of those being

informed in the nursing and/or medical notes. It might also be appropriate to consider a 'de-briefing', giving professionals a chance to discuss how they felt the meeting with the sufferer went. This aims to eliminate any undue stress related to being exposed to difficult situations, otherwise it may well present later in the form of an inability to cope with a similar situation.

4.4.1 A model of how to break bad news

Buckman (1992) suggests that what concerns many professionals about the prospect of breaking bad news are fears of causing pain, being blamed for the news and the shame of being shown up because of not knowing the answers to questions that may arise. He presents a model of how to 'break bad news' to patients (i.e. degenerative or fatal diagnoses), and it consists of six steps mainly concerning disclosure of a diagnosis to a patient (Buckman, 1992). These steps are: getting started, finding out how much the person knows, find out how much they want to know, sharing information, identifying and acknowledging the person's feelings, and planning and following through. To outline these steps, getting started involves finding an appropriate physical context and considering who to invite. Secondly, the health professional should find out how much the patient already knows by careful listening and questioning of the patient (i.e. 'Did you think something serious was going on when ...?'). Next the professional needs to find out how much patients want to know, again by asking questions (i.e. 'Would you like to know the full details of the diagnosis?'). The professional can then move onto sharing information about a diagnosis if appropriate. An agenda is useful and professionals should share small pieces of information with the patient (and relatives), check the clients' understanding of the information shared. Identifying and acknowledging the patients feelings at this point is seen as important. Finally, Buckman suggests that health professionals should organise and plan an appropriate action, such as identifying other supports for the patient. To summarise, this model guides professionals through

assessment of the level of knowledge and the wish of patients to know their diagnosis as a guide to what to inform patients.

This model seems useful for health professionals working with people with dementia to adopt where necessary. However it is one among many, and different models are often taught on training courses for health professionals. For example, some effective nurse training models comprise of role-plays (Sablewicz, Kershaw, & Mangan, 1994b) and teaching in assessment and counselling skills (Heaven & Maguire, 1996; Parathian & Taylor, 1993). Whereas, up until about the early 1980s, trainee doctors were not taught about old age mental health issues.

It seems realistic to propose that breaking bad news could prove a difficult task for health professionals working with older adults with dementia. Breaking bad news may prompt a crisis and yet, in the long-term, may also prompt clients to manage their difficulties as they adapt to the news, use coping strategies, and contact services. The author believes that it is appropriate to assess whether to discuss with older adults the implications of their dementia. Also that, having decided it appropriate, it is important to inform a majority of those with dementia about their disease, particularly those in the early stages of dementia. This can validate sufferers' experiences and shorten a period of time when a sufferer may feel unsure and question what is going on (i.e. feel they are going mad). Section 4.5 highlights some ethical issues surrounding the process of sharing information with sufferers if appropriate. Overall, this study found that in theory participants think discussing such matters is a good idea, however, it must be seen difficult to inform clients if staff feel unprepared, or feel guilty that have not got the all answers, and cannot make matters better for the person.

4.5 ETHICAL CONSIDERATIONS OF DISCUSSING A DIAGNOSIS OF DEMENTIA

Previous research suggests that there is limited discussion of the experience of dementia, but usually in the absence of the client being told their diagnosis. This raises several interesting ethical issues. These surround the broad issue of a patients' right to be informed about a diagnosis and prognosis, and consent to treatment issues. Specific to dementia, carers may not wish their relative to be told about their illness which creates a complex situation for health professionals. These issues will be discussed below.

4.5.1 The rights of a patient

It is generally well accepted that a patient has a right to information concerning his/her future (Phillips, 1996). However, if a patient is not told about the risks of treatment, the health professional may be breaching consent and the tort of negligence (Seedhouse & Lovett, 1992). Another consequence of not being told about ones' own medical status is that a patient cannot experience autonomy. It is argued that medics and other health professionals create autonomy for patients' by removing obstacles to various human potentials, including physical, intellectual, and emotional (Seedhouse & Lovett, 1992). Thus, there is an onus on health professionals to show how the chosen course of action is to be preferred over any other. Kitwood (1995) suggests that older adults with dementia require empowerment and thus, not only families, but the sufferers themselves, need to be informed about the nature of their difficulties in order to access services, plan for the future, or even seek a second opinion. Kitwood postulates that being diagnosed with dementia affects the sufferer's view of themselves. As such, if information about the diagnosis and implications of dementia is withheld, this may also affect sufferers as individuals. The onus on health professionals' to explain their chosen course of action is perhaps disregarded when they decide whether or not to inform people with dementia about their diagnoses.

There may be a case for withholding diagnostic information if health professionals perceive an obligation to benefit patients and not harm them. This may override any requirement of not deceiving patients. For example, by definition patients with serious illnesses already have severe problems, and a doctor may add to these problems by giving patients distressing news. Moreover, the patients' prospects of integrating this information often depend crucially on their mood. Sharing news about dire diseases may undermine patients' mood and impair their prospects of managing the news and perhaps even the disease. Thus, it seems a challenging situation to find oneself in of deciding whether or not to share some potentially 'devastating' information. It is currently difficult to assess whether real harm results from honesty in response to patients who wanted reliable information about their condition, or whether real harm comes from withholding such information. This again indicates that research into the impact of sharing information with older adults with dementia would be useful.

4.5.2 Difficulties when communicating a diagnosis

A case could be proposed to support withholding information about a diagnosis from the patient if the information cannot be communicated (Gillon, 1985). This could occur either because the diagnosis is uncertain, or the patient would not be in a position to understand it (i.e. misinterpret words like 'cancer' or 'dementia'). It also could be regarded as meaningless to attempt to inform patients of the whole 'truth' because this is rarely possible. Thus, if a diagnosis is uncertain, should this information be shared with a patient if it could be incorrect? This is a frequent scenario for dementia, as a definite diagnosis can only be assured at post-mortem and health professionals rely on probable diagnoses. For those diagnosed with some diseases, for example cancer, there is more certainty about the diagnosis. However, for dementia, usually a change in an individual's functioning is noticeable before physiological evidence (i.e. of brain lesions) is available.

Such a dilemma raises several questions: can carers and/or professionals legally and ethically withhold information about a diagnosis of dementia on the grounds that it is not definite? This appears implausible and is difficult to answer, but this could be used as an 'excuse' not to inform patients about their diagnosis of dementia. In addition, some researchers propose that people with dementia retain a capacity to communicate and to describe their experience of dementia (Goldsmith, 1996). Thus, it may be possible to ask, or infer through questioning, older adults with dementia whether they want to be told about the implications of their disease.

4.5.3 The wishes of people with dementia and their carers

As is sometimes the case, carers may believe that their relative with dementia does not want to be told about their diagnosis and prognosis (Phillips, 1996). As such, carers will often know more about their relatives' illness than the sufferers themselves (Brodaty *et al.*, 1990). This could be seen as a breach of confidentiality according to the law, that carers know more than the patient (Kennedy & Grubb, 1989). However, the other side of the coin must also be considered, in that patients may not want to be told the truth when it is 'dire', particularly if they have a fatal or degenerative condition (Gillon, 1985). This raises important issues for health professionals to consider.

Most of the ethical issues outlined above are drawn from medical ethics which mainly concern whether to share a diagnosis, which is not directly what this study addresses. However, it seems often the case that people with dementia are not informed about their diagnosis and prognosis because both health professionals and caregivers have genuine reasons to withhold this information.

4.6 FUTURE RESEARCH

Completion of this study has suggested a number of areas in which further research may contribute to current knowledge about the process and frequency of discussing with older adults the implications of their dementia. This study has also contributed to knowledge concerning health professionals' behaviour, and further areas of research could be suggested. Some of these are outlined below.

4.7 CONCLUSIONS

4.6.1 Future research into dementia

This study provided no evidence to suggest what the consequences are for older adults following a discussion about the diagnosis and implications of their dementia. It seems an important area to investigate these consequences as both positive and negative consequences may occur for the sufferer, their family, or the health professional who informed the sufferer. Future research into this area might inform training programmes for health professionals. For example, professionals may require training in skills appropriate to manage any negative consequences or the 'aftermath' for the sufferer. They may also require training in how to build upon positive consequences, such as, encouraging the sufferer to engage in treatment.

If health professionals decide to discuss with older adults the implications of their dementia, it seems likely that sharing this information with the sufferer may prove difficult. It would be useful to investigate effective techniques a professional could use to facilitate the sufferers' understanding of the discussion. Future research into this area may also add to a training programme. Finally, it would be useful to investigate what other factors are important when deciding to discuss dementia with sufferers in general, as this study explained less than a quarter of the variance in behavioural intention.

4.6.2 Future research into health professionals' behaviour

The Theory of Planned Behaviour may prove useful to investigate other, more concrete, behaviours of health professionals. Alternatively other theories could be employed, such as clinical judgement-analysis, already used to investigate clinical decision-making in rheumatology (Kirwan, De Saintonge & Joyce, 1990).

4.7 CONCLUSIONS

The major conclusions drawn from this study were:

1. Most participants in this study indicated that they would be likely to discuss with their clients the implications of their progressive memory problems.
2. In descending order, the predictive factors which influenced participants to discuss such matters were: subjective norm, anxiety, and perceived behavioural control
3. The results of this study imply an intervention with staff culture and, where appropriate, change of staff perception of the social norm.
4. This study also implies an intervention of staff training programmes.

Section 5

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Section 6

APPENDICES

Health professionals discussion of dementia with older adults: an application of the Theory of Planned Behaviour

Please complete all questions according to:

- **your current working practice,**
- **your current main work setting, and**
- **the older adults you work with.**

I realise that parts of this questionnaire may appear repetitive. The format is designed to fit in with a particular theory. Space will be provided at the end for your comments about the questionnaire which will be welcome.

In this questionnaire, most questions make use of rating scales with seven places. Please make a cross mark in the place that best describes your opinion. For example, if you think the weather in England is extremely good, then you would mark the scale as follows:

Extremely Good : X :

Extremely Bad

If you think the weather in England is quite bad, then you might place your cross mark as follows:

Extremely Good : : : : : X : : : : : Extremely Bad

In making your ratings please:

- Place your cross marks in the *middle of spaces*, not on the boundaries:

like this not this

- Answer all the questions and work steadily through them without leaving any out
- Put only one cross mark on each single scale

If you would like further information about this research, please contact: Suzanne Whitehead, Trainee Clinical Psychologist, Department of Clinical Psychology, Isis Education Centre, Warneford Hospital, Roosevelt Drive, Headington, Oxford OX3 7JX Tel. (01865) 226431

Thank you for your interest in this research

Appendix 2: Design and layout of the revised questionnaire

The revised questionnaire used as part of the main study is presented overleaf. The questionnaire was printed on two sides of the page, and comprised of sheets four of paper in total. These four sheets plus the information and instructions sheets were sent to nurses and psychologists. For this appendix section, the pages of the questionnaire will be presented on one side of paper, totalling eight sheets.

memory problems with older adults I work with

These tick are for

Not at all

1 - 3

4 - 6

7 - 9

10 or more

Now please read this paragraph carefully:

Mrs Smith is in her early 70s. You have seen her following a referral from her GP, who has said that she has become increasingly forgetful over the last few months. She has started to forget the names of people she knows well and, when you see her, she sometimes forgets both the date and the day of the week. She has had two 'near falls' in her own home and is now about driving now. Overall her symptoms appear typical of mild dementia.

3. At some time during the month following her initial referral, how likely is it that you would talk to Mrs Smith about the implications of her presenting a memory problem?

Extremely

Extremely

likely

unlikely

4. At some time during the next month:

The thought of talking to older adults I work with about the implications of their presenting memory problems makes me feel:

Very

Very

Anxious

Anxious

Part 1

This section asks about **your intention** to talk to older adults you work with about the implications of their progressive memory problems (dementia).

1. At some time during the next month:

How likely is it that you will discuss the implications of dementia with these older adults ?

Extremely _____ Extremely

Likely : _____ : Unlikely

2. Over the past month how many times have you talked about the implications of progressive memory problems with older adults at work ?

Please tick one box

Not at all

1 - 3

4 - 6

7 - 9

10 or more

Now please read this paragraph carefully

Mrs Smith is in her early 70's. You have seen her following a referral from her GP. It appears that she has become increasingly forgetful over the last twelve months. Recently she started to forget the names of people she knows well and, when you saw her, she was unclear about both the date and the day of the week. She has had two 'scrapes' in her car and is less confident about driving now. Overall her symptoms appear typical of mild dementia.

3. At some time during the month following her initial referral, how likely is it that you would talk to Mrs Smith about the implications of her progressive memory problems ?

Extremely _____ Extremely

Likely : _____ : Unlikely

4. At some time during the next month:

The thought of talking to older adults I work with about the implications of their progressive memory problems makes me feel:

Very _____ Not at all

Anxious : _____ : Anxious

5. Older adults accepting various treatments offered to

Extremely

Desirable

6. Older adults forgetting what was talked about

Extremely

Desirable

7. Older adults becoming depressed if

Extremely

Desirable

Part 2

In this section I am interested in your attitude to talking to older adults you work with about the implications of their progressive memory problems.

Please rate your attitude on the following scales and consider the older adult's perspective.

In your opinion, talking to older adults you work with about the implications of their progressive memory problems at sometime over the next month is, for them:

- Useful : _____ : Useless
- Harmful : _____ : Beneficial
- Good : _____ : Bad
- Rewarding : _____ : Punishing
- Unpleasant : _____ : Pleasant
- Desirable : _____ : Undesirable

Talking to older adults you work with about the implications of their progressive memory problems may result in a number of possible consequences.

Please rate how desirable or undesirable you think these consequences are:

1. Older adults gaining a better understanding of their progressive memory problems is:
Extremely Desirable : _____ : Extremely Undesirable
2. Older adults making plans for the future (eg. financial, type of care) is:
Extremely Desirable : _____ : Extremely Undesirable
3. Older adults becoming emotionally distressed is:
Extremely Desirable : _____ : Extremely Undesirable
4. Older adults starting to cope with their progressive memory problems is:
Extremely Desirable : _____ : Extremely Undesirable
5. Older adults accepting various treatments offered is:
Extremely Desirable : _____ : Extremely Undesirable
6. Older adults forgetting what was talked about is:
Extremely Desirable : _____ : Extremely Undesirable
7. Older adults becoming depressed is:
Extremely Desirable : _____ : Extremely Undesirable

8. Older adults becoming better informed about the nature of dementia is:

Extremely Desirable :-----: Extremely Undesirable

9. Older adults becoming frightened about the future is:

Extremely Desirable : _____ : **Extremely Undesirable**

10. Older adults having a health professional acknowledge the problems they are experiencing is:

Extremely Desirable : : : : : : : : : Undesirable

Now please rate how likely or unlikely you think it is that each of these consequences would occur if you talked to older adults you work with about the implications of their progressive memory problems:

1. S/he would gain a better understanding of the progressive memory problems

Extremely Likely : : : : : Extremely Unlikely

2. S/he would make plans for the future (eg. financial, type of care)

Extremely Likely : : : : : Extremely Unlikely

3. S/he would become emotionally distressed

Extremely : : : : : **Extremely**

Likely : : : : : **Unlikely**

4. S/he would start to cope with the progressive memory problems

Extremely Likely		Extremely Unlikely
---------------------	--	-----------------------

5. S/he would accept various treatments offered

Extremely Likely : : : : : : : : : : Extremely Unlikely

6. S/he would forget what was talked about

Extremely Likely : : : : : : : : : : Extremely Unlikely

7. S/he would become depressed

Extremely Likely : : : : : Extremely Unlikely

8. S/he would be better informed about the nature of dementia

Extremely Likely		Extremely Unlikely
---------------------	--	-----------------------

9. S/he would become frightened about the future

[illegible]

10. S/he would have a health professional acknowledge the problems being experienced

[illegible]

Part 3

In this section there is a list of people who you may work with. I would like to know how you think these people would like you to act. Particularly think about this next month and your main work setting. If you do not work with these people please make your best guess about what they may think.

1. In general:

Most people who are important to me think I should talk to older adults I work with about the implications of their progressive memory problems.

Strongly

Strongly

Agree : _____ : _____ : _____ : _____ : _____ : _____ : Disagree

2. At work:

The **colleagues I admire the most** think I should talk to older adults about the implications of their progressive memory problems.

Strongly

Strongly

Agree : _____ : _____ : _____ : _____ : _____ : _____ : _____ : Disagree

3. In particular:

The GP thinks that I should talk to older adults I work with about the implications of their progressive memory problems

Strongly

Strongly

Agree : : : : : : : Disagree

4. **The Consultant Psychiatrist** thinks that I should talk to older adults I work with about the implications of their progressive memory problems

Strongly

Strongly

Agree : : : : : Disagree

5. **The older adults I work with** think that I should talk to them about the implications of their progressive memory problems

Strongly

Strongly

Agree : _____ : _____ : _____ : _____ : _____ : _____ : Disagree

6. **The family of the older adults** think that I should talk to their older relatives about the implications of their progressive memory problems

Strongly

Strongly

Agree : _____ : Disagree

7. **The colleague I admire most** thinks that I should talk to the older adults I work with about the implications of their progressive memory problems

Strongly

Strongly

Agree : : : : : Disagree

8. **The main carer of the older adults** think that I should talk to their older relatives about the implications of their progressive memory problems

Strongly

Strongly

Agree : : : : : : : Disagree

9. **The clinical psychologist/qualified nurse*** thinks that I should talk to the older adults I work with about the implications of their progressive memory problems

Strongly

Strongly

Agree : : : : : : : Disagree

*Delete as applicable ie. if you are a nurse please rate what a psychologist may think.

Would you say that generally speaking, over the next month:

Part 4

In this section there is a list of factors or conditions which may make it easier to talk to older adults you work with about the implications of their progressive memory problems. Please think about your main setting and how you might act during the next month.

First please evaluate these:

1. If I wanted to, I could easily talk to older adults I work with about the implications of their progressive memory problems

Strongly Agree : _____ : _____ : _____ : _____ : _____ : _____ : Strongly Disagree

2. If I talked to older adults I work with about the implications of their progressive memory problems, it would be:

Extremely Easy : _____ : _____ : _____ : _____ : _____ : _____ : Extremely Difficult

3. How much control do you feel you have over whether you do or do not talk to older adults you work with about the implications of their progressive memory problems ?

Complete Control : _____ : _____ : _____ : _____ : _____ : _____ : Very Little control

4. How confident do you feel about your ability to talk to older adults you work with about the implications of their progressive memory problems ?

Complete Confidence : _____ : _____ : _____ : _____ : _____ : _____ : No Confidence

Please rate how likely or unlikely you think it is that each of the following will occur which may make it easier to talk to older adults you work with about the implications of their progressive memory problems:

1. Having written information about dementia to give to older adults is:

Extremely Likely : _____ : _____ : _____ : _____ : _____ : _____ : Extremely Unlikely

2. Having time to spend talking with older adults is:

Extremely Likely : _____ : _____ : _____ : _____ : _____ : _____ : Extremely Unlikely

3. Older adults being upset is:

Extremely Likely : _____ : _____ : _____ : _____ : _____ : _____ : Extremely Unlikely

4. Having a team assessment suggestive of progressive memory problems is:

Extremely Likely : _____ : _____ : _____ : _____ : _____ : _____ : Extremely Unlikely

5. Having adequate service provision to refer older adults to (eg. for treatment or support) is:

Extremely Likely : _____ : _____ : _____ : _____ : _____ : _____ : Extremely Unlikely

6. My having the appropriate skills to talk to older adults about the implications of their progressive memory problems is:

Extremely Likely : _____ : _____ : _____ : _____ : _____ : _____ : Extremely Unlikely

7. Having access to an appropriate (eg. quiet/private) environment to talk is:

Extremely Likely : _____ : _____ : _____ : _____ : _____ : _____ : Extremely Unlikely

8. Having a good relationship with older adults I work with is:

Extremely : : : : : **Extremely**

Likely : : : : : **Unlikely**

9. Having good relationship with the carers of the older adults I work with is:

Extremely Likely : : : : : **Extremely Unlikely**

Now please rate the extent to which each of these would increase the likelihood that you would talk to older adults you work with about the implications of their progressive memory problems:

1. If I had written information about dementia to give to older adults, talking to them would be:

[illegible]

2. If I had more time to spend talking with older adults, talking to them would be:

[illegible]

3. If the older adult was upset, talking to them would be:

[illegible]

4. If the team assessment provided evidence suggestive of progressive memory problems, talking to them would be:

Less Likely	More Likely
1	10
2	9
3	8
4	7
5	6
6	5
7	4
8	3
9	2
10	1

5. If I had adequate service provision to refer older adults to (eg. for treatment of depression), talking to them would be:

Less	Men
Likely :	Likely

6. If I had the appropriate skills to talk to older adults about the implications of their progressive memory problems, talking to them would be:

[illegible]

7. If I had access to an appropriate (eg. quiet/private) environment, talking to them *would be*:

Less Likely : : : : : More Likely

8. If I had a good relationship with older adults I work with, talking to them would be:

Less Likely : _____ : More Likely

9. If I had a good relationship with the carers of the older adults I work with, talking to them would be:

Less Likely	More Likely
1	10
2	9
3	8
4	7
5	6
6	5
7	4
8	3
9	2
10	1

Please make your best estimate about what your feelings would be:

At some time over the next month:

If I did talk to older adults I work with about the implications of their progressive memory problems, I would be:

Very _____ : Not at all
Anxious _____ : Anxious

Part 5

This section asks you about some personal details which will remain confidential.

1. Do you spend most of your time working in mental health settings with older adults with:

'Organic' difficulties
'Functional' difficulties

Please tick one box

<input type="checkbox"/>
<input type="checkbox"/>

2. Do you currently work in:

Memory clinic
Community Setting
Ward Setting
Residential Service
Day Hospital/Unit
Other

Please tick all boxes which apply and put an * asterisk next to the one you spend most of your time

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

Please specify.....

3. What gender are you ? MALE

FEMALE

<input type="checkbox"/>
<input type="checkbox"/>

4. What is your profession ?

Nurse

Clinical Psychologist

Please tick one box

<input type="checkbox"/>
<input type="checkbox"/>

5. How long have you been qualified ?

_____ years/months*

*Delete as applicable

6. How long have you worked with older adults in mental health settings since you qualified ?

_____ years/months*

7. How long have you worked with older adults with progressive memory problems ?

_____ years/months*

8. Date of completing this questionnaire is: _____ 1997

Part 6

As part of this research it will be necessary to re-contact some participants. Would you be willing to be re-contacted for a further stage in this study ? If so please provide your name and address below. The information given will remain confidential and will not be used for any other purpose. On completion of this research, these records will be destroyed.

Name: _____

Address: _____

_____ Post Code _____

You may like to add comments of your own about this questionnaire which will be read with interest. Space is provided here, and please feel free to write on an additional page.

Thank you for taking the time to complete this questionnaire

Suzanne Whitehead

Appendix 3: Design and layout of the revised information sheet

One minor difference existed between the information sheets distributed to the two professional groups, nurses and clinical psychologists. For this appendix section only the information sheet designed for nurses will be presented overleaf. The difference between the information sheets concerned how clinical psychologists could obtain details of the results of this study. As such, paragraph six on the information sheet was different for the two professions. For clinical psychologists paragraph six was replaced with:

I intend to publish the results of this study in the PSIGE Newsletter. In addition a sheet summarising the results and applications of this research will be available.

Health professionals working with older adults often deliver services to older people with progressive memory problems during their working practice. Professionals may be asked to talk about the implications of this evidence with the individual themselves or with their family or carers. The opportunity to talk may arise during work time, such as when talking to dry activities, therapy, or group interactions. Alternatively a patient may request to see a professional. The literature suggests that little is known about what older people think about the reasons for and against talking to older adults about the implications of progressive memory problems (or dementia) appear to be complex. This study aims to investigate this.

Questionnaires are being distributed to nurses and clinical psychologists to find out about their attitudes to this aspect of their work. Participation in this study is entirely voluntary. All questionnaire responses will be confidential and kept for a minimum of five years. Feedback will be fed back to the services involved in the study which will identify individual responses.

Please complete the questionnaire if you have:

- worked in this field for more than 6 months
- had clinical contact with older adults with dementia over the last 6 months
- a professional qualification as a nurse or clinical psychologist

If this does not apply to you, I would be grateful if you could either return the questionnaire to S.A.E. enclosed, or pass the questionnaire onto someone appropriate in your service.

I have discussed this study with the Directorate Manager who supports the research. I will not look at the questionnaire responses. Further details about the study can be obtained from the contact information given at the bottom of this page. I will make arrangements to discuss the results of this research to those interested. In addition a sheet summarising the results and applications of this research will be available.

This questionnaire takes twenty minutes maximum to complete.

Thank you very much for your interest in this research

Suzanne Whitehead

Please keep this sheet for your information

Contact Information:

Suzanne Whitehead, Trainee Clinical Psychologist, Department of Psychology, Education Centre, Warfield Hospital, Headington, Oxford OX3 7LF. Tel: 01865 206111

OXFORD REGIONAL TRAINING COURSE IN CLINICAL PSYCHOLOGY

Isis Education Centre
Warneford Hospital
Roosevelt Drive
Headington
Oxford OX3 7JX

Tel: Oxford (01865) 226431 Course Administrator
226364 Course Secretary
Fax: Oxford (01865) 226374

Health professionals discussion of dementia with older adults: an application of the Theory of Planned Behaviour

I am a trainee clinical psychologist conducting research on the above topic. The study investigates what factors influence health professionals decisions to talk to older adults about the implications of their progressive memory problems (or dementia). This research is being conducted as part of a Doctorate in Clinical Psychology.

Health professionals working with older adults often come across evidence suggestive of progressive memory problems during their working practice. Professionals then may or may not talk about the implications of this evidence with the individual themselves (as opposed to the family or carers). The opportunity to talk may arise during working practice, for example, in day to day activities, therapy, or group interactions. Alternatively a patient may directly ask a professional. The literature suggests that little is known about attitudes or practice in this area. The reasons for and against talking to older adults about the implications of progressive memory problems (or dementia) appear to be complex. This study aims to investigate these factors.

Questionnaires are being distributed to nurses and clinical psychologists to find out more about their attitudes to this aspect of their work. Participation in this study is entirely voluntary. All questionnaire responses will be confidential and kept in a secured filing cabinet. No information will be fed back to the services involved in the study which will identify individual responses.

Please complete the questionnaire **if you have**

- worked in this field for more than 6 months
- had clinical contact with older adults with dementia over the last 6 months
- a professional qualification as a nurse or clinical psychologist

If this does not apply to you, I would be grateful if you could either return the questionnaire in the S.A.E. enclosed, or pass the questionnaire onto someone appropriate to complete.

I have discussed this study with the Directorate Manager who supports the research, although he will not look at the questionnaire responses. Further details about the study can be obtained from the contact information given at the bottom of this page. I will make arrangements to feedback the results of this research to those interested. In addition a sheet summarising the results and applications of this research will be available.

This questionnaire takes twenty minutes maximum to complete.

Thank you very much for your interest in this research
Suzanne Whitehead

Please keep this sheet for your information

Contact Information:

Suzanne Whitehead, Trainee Clinical Psychologist, Department of Clinical Psychology, Isis Education Centre, Warneford Hospital, Headington, Oxford OX3 7JX Tel. (01865) 226431

Appendix 4: Final amendments to the draft questionnaire and information sheet

The draft questionnaire and information sheet were amended and developed to create a revised questionnaire and information sheet which were easily read. The list of changes are outlined below.

- Some items were moved in order to avoid participants responding to items based on their response to previous ones. For example, the item about past behaviour was moved to appear after the first behavioural intention item. This change was made because it was thought that the vignette affected the items following it. For example, participants may think it is socially desirable to discuss the implications of progressive memory problems with older adults they worked with, and thus following the vignette, might introduce a bias in response. In addition, one of the three behavioural intention items were deleted in the interests of a shorter questionnaire.
- One anxiety item was moved to the end of part 1 and the other to the end of part 4. The other two anxiety items were deleted as they appeared to add little useful information.
- The wording was clarified for the short preambles to each section. For example, the preamble for part 3 was changed from 'how much' to 'how likely' because this appeared clearer to read and the wording tenses were more accurate.
- In part 3 it was decided that the scale end words should be 'strongly dis/agree' for the global direct measures as this read better for the section.
- The information sheet was amended so that it was relevant to both nurses and clinical psychologists highlighting that the investigator had spoken to local clinical psychologists who supported the study and nurse managers. It was also indicated how the results of the study would be disseminated to the participants.
- The information sheet was also amended to include some examples of when participants might be asked about dementia by patients.

This questionnaire takes twenty minutes maximum to complete

Thank you very much for your interest in this research

Suzanne Whitehead

Please keep this sheet for your information

Contact Information:

Suzanne Whitehead, Trauma Clinical Psychologist, Department of Trauma and Critical Care, Education Centre, Warneford Hospital, Headington, Oxford OX3 7JX, UK (01865) 206111

Appendix 5: Amendments made to the information sheet (test-retest)

OXFORD REGIONAL TRAINING COURSE IN CLINICAL PSYCHOLOGY

Isis Education Centre
Warneford Hospital
Roosevelt Drive
Headington
Oxford OX3 7JX

Tel: Oxford (01865) 226431 Course Administrator
226364 Course Secretary
Fax: Oxford (01865) 226374

**Health professionals discussion of dementia with older adults:
an application of the Theory of Planned Behaviour**

I am a trainee clinical psychologist conducting research on the above topic and have already been in touch with you. The study investigates what factors influence health professionals decisions to talk to older adults about the implications of their progressive memory problems (or dementia).

As part of the study I need a small percentage of the original group who completed the questionnaire to complete a second questionnaire. This will help me assess test-retest qualities of the questionnaire in order to establish the trustworthiness of the results. Therefore I would be most grateful if you could complete a second questionnaire according to your views and working practice over the past month.

Questionnaires are being distributed to nurses and clinical psychologists to assess test-retest qualities. Participation in this study is entirely voluntary. All questionnaire responses will be confidential and kept in a secured filing cabinet. No information will be fed back to the services involved in the study which will identify individual responses.

Please complete the questionnaire **if you have**

- worked in this field for more than 6 months
- had clinical contact with older adults with dementia over the last 6 months
- a professional qualification as a nurse or clinical psychologist

If you do not want to complete a second questionnaire, I would be grateful if you could return the questionnaire in the S.A.E. enclosed.

I have discussed this study with the Directorate Manager who supports the research, although he will not look at the questionnaire responses. Further details about the study can be obtained from the contact information given at the bottom of this page. I will make arrangements to feedback the results of this research to those interested. In addition a sheet summarising the results and applications of this research will be available.

This questionnaire takes twenty minutes maximum to complete.

Thank you very much for your interest in this research
Suzanne Whitehead

Please keep this sheet for your information

Contact Information:

Suzanne Whitehead, Trainee Clinical Psychologist, Department of Clinical Psychology, Isis Education Centre, Warneford Hospital, Headington, Oxford OX3 7JX Tel. (01865) 226431

Suzanne Whitehead

Appendix 6: Amendments made to part 5 of the revised questionnaire

This section asks you about some personal details which will remain confidential.

1. Do you spend most of your time working in mental health settings with older adults with:

Please tick one box

'Organic' difficulties

<input type="checkbox"/>
<input type="checkbox"/>

'Functional' difficulties

2. Do you currently work in:

Please tick all boxes which apply and put an * asterisk next to the one you spend most of your time

Memory clinic

<input type="checkbox"/>
<input type="checkbox"/>

Community Setting

<input type="checkbox"/>
<input type="checkbox"/>

Ward Setting

<input type="checkbox"/>
<input type="checkbox"/>

Residential Service

<input type="checkbox"/>
<input type="checkbox"/>

Day Hospital/Unit

Other

Please specify.....

3. What gender are you ? MALE

<input type="checkbox"/>
<input type="checkbox"/>

FEMALE

4. What is your profession ?

Please tick one box

Nurse

<input type="checkbox"/>
<input type="checkbox"/>

Clinical Psychologist

5. How long have you been qualified ?

_____ years/months*

*Delete as applicable

6. How long have you worked with older adults in mental health settings since you qualified ?

_____ years/months*

7. How long have you worked with older adults with progressive memory problems ?

_____ years/months*

8. Date of completing this questionnaire is: _____ 1997

Part 6

As part of this research you have been re-contacted. Thank you for completing a second questionnaire to help with the re-test statistics. Please provide your name and address once again so that it is possible to compare your individual responses. The information given will remain confidential and will not be used for any other purpose. On completion of this research, these records will be destroyed.

Name: _____

Address: _____

_____ Post Code _____

You may like to add comments of your own about this questionnaire which will be read with interest. Space is provided here, and please feel free to write on an additional page.

Thank you for taking the time to complete this questionnaire

Suzanne Whitehead

Appendix 7: Correspondence with three Research Ethics Committees

Three proposals for Research Ethics Committee approval were sought from three local regions. Just one of the proposal forms will be presented as the other two are similar in content. Relevant correspondence with these Committees is presented along with the final letters of approval from all three Committees.

Before completing this form, it is essential that you fill in the following information for the Applicant's. Please provide a copy of the completed form to the relevant Research Ethics Committee.

1.	Title of project	Health professionals' experience of working with people with mental health problems
2.	Investigators	Dr Philippa Gentry, Lecturer in Health Psychology, University of Exeter
3.	Name and Title of Key Stakeholder	Mr. Stephen White, Head of Health Psychology, University of Exeter
4.	Project Description	Regional Training Course in Health Psychology
5.	Qualifications	Regional Training Course in Health Psychology, University of Exeter
6.	Data contact	Dr P. Gentry and Dr S. White, Health Psychology, University of Exeter
7.	Address for correspondence and project location (work and home)	University of Exeter, Exeter, Devon, UK

CONFIDENTIAL

APPLICATION NUMBER.....

HEALTH AUTHORITY

PSYCHIATRIC RESEARCH ETHICS COMMITTEE

APPLICATION FORM

Before completing this form, it is essential that you read the attached Guidelines for Applicants. Eleven copies of the completed form are required.

1. Title of project

Health professionals discussion of dementia with older adults; an application of the Theory of Planned Behaviour

2. Investigators

Name and title of Responsible Investigator

Dr Philippa Garety, Academic Director of Oxford Regional Training Course in Clinical Psychology

Name and Title of Key Investigator

Ms. Suzanne Whitehead BSc., Trainee Clinical Psychologist, Oxford Regional Training Course in Clinical Psychology.

Post Responsible Investigator's post is Academic Director of the Oxford Regional Training Course in Clinical Psychology

Key investigator's post is Trainee Clinical Psychologist

Qualifications Responsible Investigator: Dr Philippa Garety, MA., M.Phil., PhD., C.Psychol., and Fellow of British Psychological Society.

Key Investigator: Ms. Suzanne Whitehead, BSc.

DHA contract Dr P. Garety and S. Whitehead both have contracts with Health Care Trust

Address for correspondence and phone numbers
(work and home) See page 2

Responsible Investigator:

Dr Philippa Garety, Academic Director, Department of Clinical Psychology, Isis Education Centre, Warneford Hospital, Warneford Lane, Headington, Oxford OX3 7JX

Direct Line 01865-226434

OR Tel No. 01865-226431 Course Administrator

Key Investigator:

Suzanne Whitehead, Trainee Clinical Psychologist, Isis Education Centre, Warneford Hospital, Warneford Lane, Headington, Oxford OX3 7JX

Tel. No. 01865-226431

3. **Places where the research will be done (including other sites)**

Participants to be recruited from several Older Adult Psychiatric services in the region and the key investigator will contact all the appropriate Research Ethics Committees. Places where the research will be done include the

services for older adults based at

and services for older adults in

The investigator is currently submitting proposals to the appropriate Research Ethics Committees and does not know the outcome of these proposals as yet.

4. **Starting date and duration of study**

From August 1996 to July 1997

5. **Arrangements for indemnity**

Indemnity is provided through the responsible and key investigators contract of employment with Mental Health Trust. The Responsible investigator also has professional indemnity insurance from the British Psychological Society. Indemnity cover will be sort from Ms once ethical approval has been secured.

6. **Aims of the project**

1. To find out what factors influence health professionals to decide to discuss with older adults the evidence for and implications of progressive memory problems (or dementia)?
2. To find out if the Theory of Planned Behaviour model (Ajzen 1985, 1988; Ajzen & Madden, 1986) is a useful way of investigating health professionals attitudes to discussing progressive memory problems (dementia) with older adults?

7. Scientific background of the project

Research in oncology indicates a change in the attitude of health professionals to discussing a diagnosis of cancer and its implications with patients, in that they now prefer to tell cancer patients his/her diagnosis (Novack et al., 1979). Oncology literature also highlights the benefits of discussing diagnosis with clients and how this effects planning of care, emotional adjustment, and discussion of the future by the patient with relatives.

Within older adult literature, one study assessed how frequently old-age psychiatrists gave dementia patients and caregivers information about the patient's diagnosis and prognosis. Caregivers were invariably told of the diagnosis, while patients with severe dementia were almost never told, and psychiatrists' responses varied for patients with mild and moderate dementia (Rice & Warner, 1994). A separate study found that older adults would want to be told if they were diagnosed with dementia (Erde et al., 1988). Other literature outlines the benefits of early identification of dementia and diagnosis with patients. Early discussion of dementia can allow for patients to consider and plan to move to a more protective environment; and for caregivers to become involved in a support group where they can gain advice, support and information (Canadian Task Force, 1991).

To summarise, the change in attitude of health professionals to discussing a diagnosis of cancer and its implications with patients does not seem to have happened for health professionals working with older adults with dementia. The reasons why health professionals prefer not to tell patients about their diagnosis of dementia and its implications appears to be complex.

The proposed study aims to investigate the factors influencing health professionals when deciding to discuss the evidence for and implications of, progressive memory problems (dementia) with older adults. It is proposed that this study will be based on the theory of planned behaviour (Ajzen 1985, 1988; Ajzen & Madden, 1986) which is a model of human behaviour and decision-making, and will be described briefly below.

According to the theory of planned behaviour, three factors or beliefs predict how likely a person is to carry out a particular behaviour (Ajzen & Madden, 1986). These are:

1. Attitudes towards a behaviour - this is made up of both a positive or a negative evaluation of a particular behaviour and beliefs about the outcome of the behaviour (eg. exercising is fun and will improve my health).
2. Subjective norm - this is composed of the perception of social norms and pressures to perform a behaviour, and an evaluation of whether the individual is motivated to comply with this pressure (eg. people who are important to me will approve if I lose weight and I want their approval).
3. Perceived behavioural control - this is composed of a belief that the individual can carry out a particular behaviour based upon a consideration of internal control factors (eg. skills, abilities, information) and external control factors (eg. obstacles, opportunities) both relating to past behaviour.

The theory of planned behaviour has been applied to a wide variety of health-related behaviours. The theory has proved a useful model for examining various social behaviours. For example, Brubaker and Wickersham (1990) examined the role of the theory's different components in predicting testicular self-examination. This study reported that elements of the theory correlated with participants intention to perform the behaviour. The proposed study is applying the Theory of Planned Behaviour to find out what factors are important when health professionals decide to discuss dementia with patients or not.

8. Design of the project

1. Single group survey design.
2. Survey to use questionnaire to investigate staff attitudes of health professionals to discussing dementia with older adults.
3. Main analysis will be a within group multiple-regression and correlation.

9. Subjects

Healthy subjects Patients Control patients

The subjects will be nurses and clinical psychologists working within psychiatric services for older adults.

Numbers to be studied (and sex ratio)	To recruit approximately 100-200 subjects; sex ratio undetermined as yet - it is likely that the subjects will be predominately female.
Age range	Age 18 - 65 years
Inclusion	Subjects to be qualified nurses and clinical psychologists who work in older adult psychiatric services. Subjects must have worked with older adults for more than six months.
Exclusion criteria	Qualified nurses and clinical psychologists who have worked with older adults for less than six months.
Basis for choice of sample size	Sample size has been chosen in order to carry out a multiple regression analysis

10. Payment of subjects

The proposed study does not intend to pay its subjects. Subjects will be offered verbal and/or written feedback about the results of the study.

11. Mode of recruitment

It is planned to recruit clinical psychologist subjects through the Clinical Psychologist's National Special Interest Group for Older Adults.

Nursing subjects will be recruited from several services for older adults including the _____ services in _____ and _____. The investigator has liaised with Clinical Psychologists within the _____ Region who have verbally consented to support the study.

A letter will be sent to all of the older adults services involved requesting the Service Manager's consent.

12. Procedures

i) Interviews and self-report questionnaires

1. A pilot version of a questionnaire to be generated (see appendix 1 for draft pilot) derived from the model of the Theory of Planned Behaviour.

2. The pilot questionnaire to be distributed to 50 subjects, and comments will be requested from subjects about the pilot.

3. A revised questionnaire will be generated from the initial pilot questionnaire. This revised questionnaire to be forwarded to the _____ Research Ethics Committee if required.

4. The revised questionnaire to be mailed to 100 - 200 subjects.

5. A second mail-shot of the revised questionnaire will be sent to a subgroup of subjects in order to assess test-retest reliability of the revised questionnaire.

ii)

Recordings (videotape and/or audiotape)

None

iii)

Samples (arterial, venous, urine, CSF, biopsy etc.)

None

iv)

Administration of radio-isotopes

No

v)

Administration of X-rays

No

vi)

Administration of substances or agents other than drugs (e.g. diets, physical agents such as heat, radiations, etc.)

No

vii)

Other procedures (e.g. procedures from experimental psychology, psychophysiology tests, exercise tests, etc).

None

viii)

Substances to be administered

None

Drugs

1

2

3

Approved name

Proprietary name (if any)

Formulation

Dose

Frequency

Route

Possible complications (append details if necessary)
MCA status and number *
PL/CT/CTX/DDX

* MCA (Medicines Control Agency)

PL (Product licence) - append a copy of the relevant data sheet.

CTC/CTX (Clinical Trial Exemption) and DDX

(Doctors and Dentists Exemption) - append a statement on the adverse effects and long-term safety of the drug, and a copy of the certificate.

13. Information and consent

Consent of the various Service Managers will be secured. An information sheet to be sent out with the questionnaires will clarify that participation in the study is optional, voluntary and that all responses will be anonymous (see draft information sheet in appendix 2). Subjects approached will be considered to opt into the study when subjects complete the questionnaire (see appendix 3).

All information gathered will remain confidential - see section 18.

BE SURE YOU HAVE READ THE GUIDELINES FOR APPLICANTS

Remember to enclose the Information Sheet and Consent Form

Information to be given to subjects:

If you have any queries, I can be contacted as below :

See Information Sheet in Appendix 2

See Consent form in Appendix 3

14. Agreement of the responsible clinician

Not applicable.

15. Informing the patient's general practitioner

Not relevant

16. Funding

A budget of one hundred pounds has been allocated to the key investigator to cover travel expenses and the cost of photocopying the questionnaires. This has been allocated by the Training Course.

17. Material gain

Investigators do not have a financial interest in carrying out this study and will not receive any form of material gain from the study.

18. Confidentiality and data protection

All completed questionnaires will be kept in a locked filing cabinet. All results will be reported anonymously.

Subjects will be assigned a confidential identification code for data analysis purposes, known only to the key investigator. On the data analysis file, the identification codes will be used and the key to the codes will be stored at a different location to the computer file. Once data analysis has taken place, the questionnaires will be destroyed and the codes destroyed.

The information given on this application form, is to the best of my knowledge and belief, accurate. I have read the Guidelines for Applicants (10.9.93) and understand my obligations and the rights of the subjects to be studied, particularly in regard to the giving of information and the obtaining of consent.

Name of Principal Investigator... DR. PHILIPPA GARETY

Signature... *Ph Garrett*

Date... 22nd July 96

Name of Key Investigator... SUZANNE WHITHEAD

Signature... *S. Whithead*

Date... 22.7.96

Name of Second Supervisor... DAMIAN GARDNER

Signature... *Damian Gardner*

Date... 22.7.96

(7) Although the Committee does not usually require a research ethics committee to sign a form that you supplied for this purpose, it is recommended that you do so. If you do not, the form would not be necessary for the submission of your application to the committee.

Please direct your reply and copies of any amended forms or information to the
Chairman of the Psychiatric Research Ethics Committee

Best wishes

Katy Smith

Dr

Secretary

Psychiatric Research Ethics Committee

Tel.
Fax:

8/8/96

Dept of Clinical Psychology
Isis Education Centre
Warneford Hospital

Application Number: 96/34

Title: Health Professionals discussion of dementia with older adults; an application of the theory of planned behaviour.

Dear Dr

This application was considered by the Psychiatric Research Ethics Committee at its meeting on 6th August 1996. The application was approved subject to the following conditions:

(i) Although the Committee does normally require the Royal College of Physicians consent form that you supplied, for this particular application the Committee felt that a consent form would not be necessary as completion and return of the questionnaires would indicate consent.

Please direct your reply and copies of any amended letters or information sheets, to Dr
Chairman of the Psychiatric Research Ethics Committee,

Best wishes,

Katy Smith

Dr
Secretary
Psychiatric Research Ethics Committee

OXFORD REGIONAL TRAINING COURSE IN CLINICAL PSYCHOLOGY

COURSE DIRECTOR:

Mrs. Jane Dunn, M.Phil., C.Psychol

Isis Education Centre

Warneford Hospital

Roosevelt Drive

Headington

Oxford OX3 7JX

ASSOCIATE & ACADEMIC DIRECTOR:

Dr Philippa Garety, PhD., C.Psychol

Direct Line: Oxford (01865) 226305 Jane Dunn

Oxford (01865) 226434 Dr Philippa Garety

Tel: Oxford (01865) 226431 Course Administrator

226364 Course Secretary

Fax: Oxford (01865) 226364

Dr.

Chairman of the Psychiatric Research Ethics Committee

5th September 1996

Dear Dr

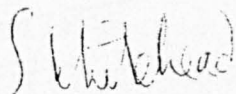
Health professionals discussion of dementia with older adults: An application of the Theory of Planned Behaviour

Application Number 96/34

I received a copy of the letter sent to Dr dated 8.8.96, concerning the above application which was submitted for ethical approval from the Psychiatric Research Ethics Committee.

The Committee provided approval for the study subject to one condition. As suggested by the Committee, I will not use a consent form as part of the study but this will be indicated through completion and return of the questionnaires. I will forward copies of any amended letters or information sheets to you for approval before going ahead with the study.

Yours sincerely,



Suzanne Whitehead

Trainee Clinical Psychologist

c.c. Dr

Course in Clinical Psychology

Oxford Regional Training

Tel:

Fax:

17 September 1996

Ms Suzanne Whitehead
Trainee Clinical Psychologist
Isis Education Centre
Warneford Hospital
Roosevelt Drive
Headington
Oxford
OX3 7JX

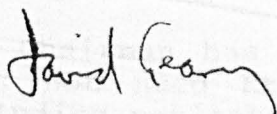
Dear Ms Whitehead

RE: OPREC APPLICATION NO: 96-34

"Health professionals discussion of dementia with older adults: An application for a planned behaviour"

Thank you for your letter of 5 September 1996. The study now has full approval

Yours sincerely



Dr
Chairman,

Consultant Psychiatrist
Psychiatric Research Ethics Committee

cc: Dr

ISIS Education Unit, Warneford Hospital

Vale Local Research Ethics Committee

Telephone
Direct Line:
Fax:

5 August 1996

Isis Education Centre
Warneford Hospital
Warneford Lane
Headington
Oxford OX3 7JX

Dear

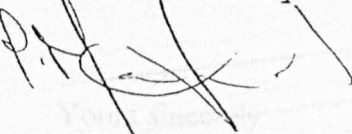
Re: Project NC704 - "Health professionals discussion of dementia
with older adults; an application of the
Theory of Planned Behaviour".

Thank you for submitting your research proposal.

The Chairman has considered your proposal and has stated that it
does not need Ethical Committee approval as it is research not
including patients.

He is therefore happy for it to proceed without Ethical Committee
approval.

Yours sincerely



Committee and Administratives Services Manager

Local Research Ethics Committee

25 September 1996

Ms Suzanne Whitehead
Trainee Clinical Psychologist
Isis Education Centre
Warneford Hospital
Roosevelt Drive
Headington
Oxford OX3 7JX

Dear Ms Whitehead,

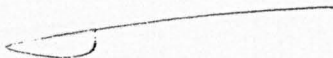
**REC308 Health professionals discussion of dementia with older adults:
An application of the theory of planned behaviour**

Thank you for your submission of the above project which was considered at the recent meeting of the LREC. I am happy to give formal approval for this study, but should like copies of the final subject information sheet and revised questionnaire when available. Please note that this approval is for a period of two years only.

We would be grateful if you would complete the enclosed R & D proformas and return them using the envelopes provided.

Good luck with the project.

Yours sincerely



pr Dr
Consultant
Chairman, Research Ethics Committee

enc:

Appendix 8: Post-test analyses for multiple regressions

Two post-test analyses were employed after the first and second multiple regression analyses (Results sections 3.4.2.1 & 3.4.3). The results are presented in Table 16.

Table 16 Post-test analyses following multiple regressions

	Z scores	Significance values (p)
Regression 1	1.61	0.01*
Regression 2	1.63	0.01*

* - $p < .05$, 2-tailed

Non-significant results from the post-test analyses for regression 1 & 2 indicated that the data is not normally distributed in both regressions. Thus, the regressions were not confirmed by post-test analyses, and the results were treated with some caution.

Appendix 9: Tests investigating differences between groups

The results of the Chi-square tests (in Results section 3.4.2.3) indicate that there was not a significant link indicating that there was more likely to be more male or female participants in either of the professions. There was not a significant link to indicated that either profession would work more predominantly with clients with organically- or functionally-based difficulties. These results are presented in Table 16 below. To summarise, no differences were found between the frequencies of gender and type of client difficulty (organically versus functionally-ill) between professions.

Table 16: Differences between professions

	Clinical Psychologists		Nurses		Chi-square significance values
	n	(%)	n	(%)	
Male	37	(20)	20	(11)	0.49 ns
Female	90	(49)	37	(20)	
Organically-ill older adults	57	(31)	35	(19)	0.06 ns
Functionally-ill older adults	70	(38)	22	(12)	

ns - non-significant *p* value.

Appendix 10: One sample Kolmogorov-Smirnov Goodness of Fit Tests

One sample Kolmogorov-Smirnov Goodness of Fit Tests (non-parametric) were used to assess whether certain variables were normally distributed and the results are summarised in Table 17. Tests investigated whether the first behavioural intention item (global question), the second behavioural intention item (vignette), and the assessments of past behaviour were normally distributed in each professional group (in Results sections 3.4.4.1 & 3.4.4.2). Tests were also used to investigate whether the first behavioural intention item (global question) data was normally distributed in each of the gender groups (Results section 3.4.4.3).

Table 17 Summary of One Sample Kolmogorov-Smirnov Goodness of Fit Tests

	Significance values with		Z scores		Normal Distribution (Yes/No)
	Men	Women	Nurses	Psychologists	
First behavioural intention item	N/A	N/A	0.02* Z=1.52	0.00* Z=2.65	No
Second behavioural intention item	N/A	N/A	0.01* Z=1.68	0.00* Z=2.69	No
Assessment of past behaviour	N/A	N/A	0.01* Z=1.67	0.00* Z=3.47	No
First behavioural intention item	0.00* Z=1.89	0.00* Z=2.39	N/A	N/A	No

N/A - test not applicable; * - $p < .05$

Table 17 summarises the results of tests to investigate normal distributions. The results indicated that nurses ($n=57$) and clinical psychologists ($n=127$) reached significance levels of $p < .05$ for the first behavioural intention item (global question). This indicates that this behavioural intention item did not have a normal distribution of responses to the first behavioural intention item in each of the professions. The results indicated that both professions reached significance levels of $p < .05$ for the second behavioural intention item (the vignette). This indicates that this behavioural intention item did not have a normal distribution of responses in each of the professions. The results for the estimation of past behaviour item indicated that both professions reached significance levels of $p < .05$. The results indicate that the past behaviour item also did not have a normal distribution of responses in each of the professions.

The results indicated that both men ($n=57$) and women ($n=127$) reached significance levels of $p < .05$ for the first behavioural intention item (global question). These results indicate that this item did not have a normal distribution of responses in each of the sexes. To summarise, results of these tests investigating normal distribution of data indicate that all the items outlined above were not normally distributed.